Home Attendants Speak About Home Care

A guide to home care, spoken by the women who provide personal assistance/home attendant care to frail elders in New York City

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Why this Manual?

"We're told what to do, but then you have to add some commonsense."

The home attendants we interviewed for this Manual stressed the need for commonsense in getting their job done. We wanted to hear more about this commonsense. How do you get a client to bathe when she doesn't want to? When do you call the family or agency supervisor, and when not? How do you reassure the person with Alzheimer's disease who forgets who you are or accuses you of stealing? And how do you say "no" to families that want you to do things that are not part of your job?

"You have to work according to your clients, not how you were taught."

Commonsense is not always obvious. You have in-services at your agency to learn about diseases (such as diabetes care), but you also learn much from experience. This is a theme that ran through our interviews with people who provide home care to older adults in NYC's Medicaid Home Care Program. Home attendants play a key role in this care. You get the job done. We decided to learn from you and put together this guide to home care. It contains information about home care *in your words*, from conversations we had with over 100 home attendants. This manual gives a picture of who you are, what you've learned on the job, and what makes home care a particular challenge. We hope it makes "being there for someone" easier and more satisfying.

Listening to You:

Learning from Home Attendants

"Experience makes the job easier, but you've got to love what you do and want to do it. The money alone won't do it."

"Home attendants," "home attendants," "home care workers," "home care paraprofessionals," or just "home attendants" – there are many titles for the work you do. The different names show how varied this work is. You do personal care tasks for clients, such as bathing, dressing, feeding, and toileting. You manage the household. You get the client to the doctor, to the store, or to day care programs. You are part of the family. For the client who lives alone and does not have family nearby, often you *are* the family. Even when families are present, sometimes you know your client better than they do. You have to be a friend and companion but also a professional.

It's difficult to wear so many hats. How do you do it? The best way to find out, we thought, was to ask you.

Who We Spoke to

In 1997-98, we contacted two home care agencies in New York City. We interviewed 72 home attendants, 25 from Bronx Jewish Community Council Home Attendant Services and 47 from Family Home Care Services of Brooklyn and Queens. In 2002, we spoke to 30 other home attendants from Family Home Care Services of Brooklyn and Queens.

What We Asked About

The interview covered many topics. Some involved your work history (how many years, how many clients, how many agencies). Some involved your health and quality of life. We asked about your client: health conditions, memory or behavior problems, and what you do for the client every day. Finally, we asked you to describe your own experiences as a caregiver: what you find hard about being a home attendant, what makes a good caregiver, what makes a good client, and how you handle a difficult client or family.

One caregiver was puzzled by all the trouble we went through to complete this project. She said home care is obvious: "Just treat a client like a person, that's all." We explained that "treating a client like a person" is really quite complicated. How do you treat someone "like a person" if they ask you to do things you shouldn't be doing – like taking care of other family members or staying later than you are required to do? Or if they are abusive or have family that interfere with your job? Or if they have dementia and try to leave home all the time? Or if they are dying and in pain?

"Treating a client like a person" is a good guideline, but how to do it may not be obvious. That's why we decided to ask you how you do it.

A Picture of Home Attendants

"I try to be nice even when clients aren't nice."

Who You Are

Home attendants in New York City are mostly women of color and many are from the Caribbean islands or South and Central America. All but one of the 100 home attendants we interviewed were women. 10% were Spanish speakers. The few women who said they were not African-American or Hispanic were recent immigrants from eastern Europe and Russia. More than half were married and had completed high school. The age of these home attendants ranged from 27 to 72; half were age 49 or older.

The women we spoke to had been home attendants, on average, for 10 years, with about 15 clients since they first began working. They had worked an average of 7 years at their current agencies. Most had long-term clients. Home attendants in our sample were almost always full-time employees. Many took on second clients for weekends or evenings.

Your Health and Quality of Life

The work is demanding, so it is not surprising to find that home attendants generally report good health. The home attendants we spoke to had high levels of energy and little depression or anxiety. About 10%, however, said they had experienced pain and had to be careful about work involving lifting or bending. Because it is an important part of your work, we need to learn more about on-the-job injuries related to lifting and other features of personal care assistance.

Who Becomes a Home Attendant?

People who become – and remain – home attendants are likely to have the kinds of personality that go with the job. Women who choose to be home attendants and hold such jobs over many years are likely to be comfortable with people, generous or altruistic, and receptive to religious experiences. As one home attendant said, "I try to be nice even when clients aren't nice." Another commented, "it's interesting to go to a new client: you never know what you'll find there."

Many of the people we interviewed came to personal care assistance work from other helping professions. Some were nurses or nurses aides, or planned to be, before starting careers in home care. Many had experience in children's day care or were teacher assistants. Some chose to become home attendants from personal experience as a caregiver to a family member.

The Needs of Clients

Clients receiving home care in New York City's Medicaid program are, on the whole, very impaired. Half the clients receiving care in our sample had difficulty with memory, and more than one-third were diagnosed with Alzheimer's disease. Nearly all were limited in their ability to walk; in fact, one of every three of these clients was confined to a bed or chair. Half had been admitted to a hospital in the prior year.

How You Spend Time on the Job

As home attendants, you provide help with all the essential "bed and body work." Almost all the clients needed help with bathing, dressing, going outside, and using the toilet. More than half the clients wore diapers and needed to be cleaned regularly. Also, half needed to be turned in bed or needed help getting in and out of bed. You also helped clients get to the doctor, use the telephone, take medications, and, in some cases, handle money.

To get an idea of how you spend time on the job, we asked home attendants to divide their day into 15-minute segments and tell us what they and their client were doing during each of these segments. We describe some of these "time diaries" here.

- The first is from a home attendant with a relatively young client (age 74), who needed help only with bathing and dressing and going outdoors. The client's major problems were arthritis and diabetes.
- The second is from a home attendant with a much older client (age 86) who had mild Alzheimer's disease and a variety of medical complications.
- The third is from a home attendant providing care to a severely affected Alzheimer's patient (age 87). She was unable to get out of bed or a chair. She also had very challenging behavior problems.
- The fourth is from a home attendant caring for a non-responsive, vegetative patient (age in the early 80's), in constant pain, who had only a few months to live.
- The fifth is from a home attendant whose client (age in mid 70's) had many chronic conditions, including seizures. The client used a variety of medical equipment (oxygen, nebulizer, wheelchair, and Hoyer Lift).

This range of patients and their disabilities illustrates well what one home attendant told us: "Be prepared for all kinds of clients!"

A young, relatively healthy client.

This client received 15 hours of personal assistance, 3 hours each day, 5 days a week. (The home attendant for this client also provided 28 hours of weekly care to a second client.) The home attendant got the client up out of bed, helped her bathe, prepared breakfast, and laid out medicines (which she completed in about 1 hour), and then spent the other 2 hours cleaning the kitchen, washing the floor, doing laundry, and going to the store. She prepared a sandwich and talked with the client over lunch. Then her work was done. The major problem reported by this home attendant was boredom.

The older client with mild Alzheimer's disease.

The home attendant provided 60 hours of care each week, 12 hours each day, 5 days a week. A second home attendant worked the other two days of the week, and the family provided night care. The client needed help with bathing, dressing, grooming, using the toilet, and transferring from bed to chair. The client cried throughout the day. Just getting her out of bed, bathed, and making sure she ate breakfast took 2 hours. The rest of the day was spent moving the client throughout the apartment, taking her to the toilet, and trying to reassure her. The home attendant would move her to the living room and do the laundry while watching her. She would move the client into the kitchen so she could keep her company while she prepared a meal. She took the client to the toilet every 2 hours because the client was incontinent. She repeated this schedule throughout the day until it was time to get the client ready for bed.

Working 12 hours a day required a routine that helped the client feel more secure in knowing what comes next. It also was a great help to the home attendant, since it allowed her to break up the day and get everything done.

The severe Alzheimer's patient, confined to bed or chair, with psychiatric symptoms.

This client received 24-hour care. The home attendant we interviewed provided 24-hour care 4 days straight -- a total of 96 hours each week. A second home attendant provided care for the other three days of the week. The patient had disturbing delusions and hallucinations every day. She thought the home attendant had stolen from her. She screamed, cursed, and even hit the home attendant. The client needed to be bathed, dressed, toileted, fed, diapered, and transferred from bed and chair.

The home attendant had to adjust her schedule to the client's pattern of sleep. The client slept on and off throughout the day and night, so that the home attendant had to sleep when the client did, in 2-3 hour stretches. We can agree with this home attendant when she said, "with certain clients we don't get to sleep." This can lead to severe stress and burn out. This home attendant contacted her supervisor to request relief.

A non-responsive, vegetative patient, in severe pain and near death.

This client did not talk or respond to questions and could not move or turn herself in bed. She stayed in bed and had to be propped up to be fed a liquid diet three times a day. Aside from preparing meals and feeding the client, the home attendant kept the patient clean with a sponge-bath each day in bed. She changed the client's diaper and turned her every 2 hours. She was with the patient 12 hours each day, four days a week. For the majority of the day the patient slept. When the client was awake, however, she was in great pain and constantly moaned and cried out. She had end-stage cancer as well as gangrene in one foot, which was not being treated.

The multiply-impaired client who depends on advanced medical technology

This client was sick "with everything." The home attendant spent 11 hours a day with her and spent almost every minute in active care: "what I do in one day is like a week-long job because she has so much to do for her." The home attendant helped with administering oxygen and a nebulizer. She recognized that this was not part of her job: "I didn't get training for it. But when you go on a case, you see the patient and you see she has to use this equipment." Here was a case where the home attendant explained to the client (and also to the agency) that this client actually needed more care than a home attendant could provide. She recognized that a home attendant who performs medical procedures outside her job description can get into serious trouble. Even though she liked her assignment and loved her client, she had to get her supervisor involved.

These kinds of clients show the range of home care. They also show the different challenges you face. In the next section of this Manual, we present guidelines – in your own words – for handling challenges related to clients and their care. But first it is important to remember who your clients are.

Knowing Your Client

People must meet certain requirements if they are to receive home attendant care. People who become home care clients usually are unable to perform at least two of the Activities of Daily Living (ADL). The ADL include feeding, transferring from bed or chair, bathing, toileting, and dressing. If people are unable to perform these activities, they have lost some of their independence. They depend on a stranger for help. The client who needs help with ADL also loses a great deal of privacy in exchange for home care. In addition to helping with these disabilities, home attendants also need to understand the emotional and psychological effects of disability on a client.

Help with ADL allows people to stay in their home. Otherwise they might have to move elsewhere or enter a nursing home. Because you allow clients to stay in their homes, home attendants are an extremely important group of caregivers. When clients are able to stay at home and maintain comfortable routines despite their disabilities, they enjoy a good quality of life.

Remembering that Your Client is a Person

Sometimes we forget that many clients have lived fruitful and productive lives. You may be surprised to learn that your client had been a teacher, librarian, chemist, nurse, or dancer. Many have raised children and help responsible jobs. The change in their status can cause serious depression and feelings of hopelessness. If the client lives to a ripe old age, she probably has outlived most of her family and friends. The client may feel totally alone. If you are sensitive to the aging process and remember that each client is a individual with a unique history, you will do a better job.

When You Have to Sleep at a Client's Home

"The hardest ones are the ones that don't sleep."

"Some nights she just wants to stay awake all night. I stay up with her.

"One stayed in her pajamas all day because she wasn't sure if it was day or night."

If you are providing personal care through the night, the client is supposed to provide a reasonable place for you to sleep, a bed. You should be able to sleep when the client is sleeping.

It is the responsibility of the nurse who evaluates the client and recommends sleep-in services to make sure there is a proper sleeping arrangement for the home attendant. If there is no proper sleeping arrangement, but the client requires round-the-clock care, the nurse should assign a split shift.

However, in some cases, clients and their families do not provide a place to sleep. One client refused to allow her 24-hour home attendant to sleep on the couch. The home attendant had to bring a sleeping bag and sleep on the floor. In this case, you should discuss sleeping arrangements with the family and call your agency. You should not accept a sleep-in assignment where there is not a proper bed, even if you need the income. If you are too tired to work because you can't sleep well, you will be exhausted and may even be too tired to carry out your duties. This may endanger the safety of your client and puts you at risk for developing physical problems, like a sore back. This can affect your future employment.

When you provide care for a client with Alzheimer's disease, your sleep may suffer. Keeping clients on a good schedule of meals and activity may help, but frequent wake-ups are common. Sleeping when the client sleeps is a common strategy.

One home attendant described a small apartment where there simply was no place to sleep. Every night she would bring a big plastic garbage bag, open it up, and lay it out in front of the refrigerator, where she would sleep. This was an unacceptable situation, and the home attendant eventually left this client.

More generally, some families may make an issue of your use of the stove, lights, refrigerator, TV, and even the toilet. You are entitled to reasonable use of these appliances, such as the stove or microwave for heating food, and certainly the toilet. This is another case where you should call the agency.

Remember, if the family cannot provide a sleep-in worker with a reasonable place to sleep, the client is not eligible for sleep-in care. The client may need to be moved to a different home. If you find yourself sleeping on a plastic bag, an uncomfortable couch, or any other unsatisfactory sleeping arrangement, you should notify your agency.

It may be difficult to complain to your agency. Some home attendants hesitate to complain about working conditions because they need the job and fear they may lose it if they complain. But all home care agencies have procedures for bringing problems to the attention of supervisors. Take advantage of these procedures. No worker can be expected to perform her job well when sleeping arrangements are unacceptable.

When You Share Care for a Client

"You've got to do your job, like cleaning up a client who is incontinent, and not leave it for the next home attendant."

You may share care for clients who can't be left alone or who need help with nearly all their basic needs. These clients receive help from 2 or even 3 home attendants each week. Families may have a different arrangement with each home attendant. You may step into a situation without knowing what these arrangements are.

What you do may make the job harder or easier for other home attendants. Home attendants said they tried not to shift work on to the next home attendant. They do not leave the sink full of dishes, and they make sure clients are clean, fed, and dressed appropriately before they leave. This is a sign of professional behavior and courtesy to your co-workers.

Sometimes a client may play one worker against another as a way of establishing a closer relationship with you. She may say how displeased she is with the other worker and swear you to secrecy. While you may be flattered to be the "favorite" home attendant, beware. You may think you have a good relationship with the client, but you can be sure that sooner or later your client will begin to criticize you if the worker she didn't like is replaced by someone she likes even better than you. It is best to tell the client to speak directly to the worker.

Always keep in mind that your job is to help your client stay as well and as comfortable as possible. If your co-worker is in fact slacking off or is in some way not fulfilling her contract, you might try to bring it to her attention in as gentle a way as possible. Nobody likes criticism, especially from a co-worker. It is not an easy thing to do.

If there is no improvement in the situation and you feel your client has a legitimate complaint, you may need to discuss it with your supervisor. Under no circumstances should you enter into a conspiracy with your client or gossip about your co-worker. You will always get

When Your Client is Agitated

"You've got to know how to handle a client and how to handle yourself."

"If a client yells, she doesn't know what she's doing. You've got to try to quiet them down. You've got to mellow them down."

"She acts up and yells and screams. I've seen her rip off her diaper. She threatens me and has complained about me to my coordinator. Not only that: she sleeps a lot during the day rather than the night, which makes it worse."

One client went mad. She threw the telephone at me. Then she called me the devil and said I had locked her in the basement!"

I had one who said she would throw herself out the window. I wanted to call 911. But the client threatened me and said she would tell EMS that I pushed her! I reasoned with her and managed to calm her down."

Caring for agitated clients may be the most challenging and demanding kind of care. To carry out personal care tasks, such as bathing and toileting, you need to manage these extremely difficult behaviors. Agitated clients may hit you and also abuse you verbally. It is disturbing to see clients do strange things, such as pull on their skin and injure themselves, or tear off their clothing, or insist that an ordinary object is something else. Even when these clients are not aggressive, just being near them can make you feel strange and uncomfortable. If you work with these kinds of clients, "you've got to know how to handle a client and how to handle yourself." You may need to call your supervisor and get help in coming up with strategies to handle these behaviors.

Many personal attendants confessed that continual care for the agitated client was too much for them. When you feel that way, you are at risk of burn-out and should consider calling your agency and asking for a new placement.

Agitated clients usually have a form of Alzheimer's disease. Alzheimer's damages a client's memory, attention and concentration, and judgment, and ultimately a client's ability to speak and care for herself. Alzheimer's patients lose the ability to sort out information about what is happening around them. As a result, the world seems chaotic and threatening. Some clients respond by insisting that people have stolen objects (if they can't find something they have misplaced), or that their house is someone else's or that you are someone else (if they do not know where they are). These behaviors are extremely hard to handle and are part of Alzheimer's care (see next section).

When Your Client Has Dementia or Alzheimer's Disease

"You have to remind them of things, even eating. They forget and do inappropriate things, and they can't help themselves. But, you know, she still says 'thank you' and then I know that she's satisfied and I'm doing her well."

"She had dementia. She could be nice and she could be mean. She didn't want to bathe. She would lay there and say she already did! She gave me a hard time. She wanted to beat me up!"

"One Alzheimer's patient was very difficult. She was aggressive and violent. She scratched me in the face. Her son intervened, but I asked for another assignment."

The home attendants we spoke to all had experience caring for clients with Alzheimer's disease. About one of every three clients had Alzheimer's, and our home visits showed that a majority of clients had some loss of memory.

Home attendants are well aware of the particular challenges of Alzheimer's care. Apart from agitation, these patients may be particularly demanding, as even very simple tasks become difficult and frightening to them. Each home attendant had seen the confusion and disorientation typical of the disease.

"She calls out for me every 5 minutes. I talk to her and tell her to sit down. I have to cope with it."

"She misplaces things. She tells me one thing one minute and then something else the next. Then she curses me!"

"I had one Alzheimer's client. I never knew what to expect every day for 2 years. I was glad when it was over. The whole time I never could understand her."

You mentioned many strategies, "tricks," to make caregiving easier. This is the sign of an experienced Alzheimer's home attendant:

"She talks to people who aren't there. So I talk to her."

"She thinks people steal from her and complains. So I stay away from her dresser drawers."

Engaging Alzheimer's clients in activity, when possible, is a good strategy. Home attendants tried to get their Alzheimer's clients to talk, to think about the past, and reminded them where they were. They also sought to involve clients in their own care and used the home environment as a source of stimulation and comfort.

"I show my clients pictures of their families. That gets them talking."

"You've got to talk to them. You have to keep them going. I joke with them."

"Be with them and help them. Tell them the day and time and when any holidays are coming. Repeat things."

"She doesn't remember anything. So I talk to her and remind her about things. She gets mad about it, but I know how to remind her without getting her mad."

"Keep things the same every day, over and over. That helps."

"Keep everything the client is accustomed to exactly as it is. Don't change a thing."

The combination of poor sleep, agitation, and need for constant supervision makes Alzheimer's care extremely difficult. The best advice is to take the challenge day by day but also to watch patients as carefully as possible: "I have to keep my eyes on her all the time so she doesn't hurt herself. That's hard." Or, as one aide put it: "Try not to get angry. Concentrate on the job, not the person."

When a Client's Home Is Dangerous

Client's homes can be dangerous, either because the client is violent or because the home or building is unsafe. One home attendant described a violent client who threw bottles, called the police, and threatened the home attendant with a cane: "We had to take everything out. No knives, nothing. I had to put knives in the drawers and lock them up. Anything that could be dangerous. Then she tried to hit me with the cane!"

Home attendants stressed that it is wise to beware of dangers even when buildings or neighborhoods do not look threatening. "I don't care how dangerous the neighborhood is, or the projects. It doesn't matter. It can be in a project; it could be in a nice neighborhood. Anything can happen."

Home attendants suggest two strategies for potentially dangerous buildings. First, you can choose not to accept an assignment. "We have a choice. If we are sent on a case, you stay the first day. If you don't like it, call your supervisor and say, 'The client is OK, but the neighborhood is dangerous and I don't want to go back there."

A second strategy is to establish your position as a home attendant and to get to know people in the building. "When I go into a project, when I see the people there, the first thing I do is introduce myself. Whoever I meet downstairs, the first time, I introduce myself. I say I am here to work, and ask if I can count on them to help me do my job."

Agencies have a night time service, so even during the night you can call the agency if you feel unsafe. Or you might have to protect yourself more directly and call 911. "If it's a dangerous situation where you are going to be hurt, you take yourself out of there. I mean, you don't go away. You open the door and stand outside. If you're in danger, you call the agency, you call the family, you take yourself out of there, but you call 911." Since you cannot leave the client alone, and since the agency will need to call you back, you should not leave the home unless you are in immediate danger.

Home attendants mentioned the many advantages of carrying a cell phone. If you are asked to work in a dangerous neighborhood and don't have your own cell phone, try talking to a supervisor to see if the agency can provide a cell phone.

When a Client Refuses Your Help

One client, an elderly recluse who was also severely disabled, posed a major home care challenge. Living alone, she had not bathed in close to a year and ate an extremely limited diet, when she ate at all. Home attendants had come and gone over the year, but none were able to get her to cooperate or bathe. The client would not even let them touch her. Her family had given up. She was in danger of being placed in a nursing home. The agency was also about to give up: they had given the home attendant permission to skip bathing care for this women and simply feed her. At this point, a particularly effective home attendant was sent to the home. She describes what happened next in this way:

I said to her, 'It's not right for me just to feed you. My job is to keep you clean.' I said, 'We will take our time and get you into the shower.' I thought: 'she's a human being and needs a shower.' It took a month, but I got her into the shower. It happened this way. One morning, she was a mess. I said, 'You have to shower, no matter how much you scream. Take your time; I'll help you.' I showered her. The shower was medicine. After, she said she couldn't believe the difference, and the next day she was willing.

Also, she only ate bread. The agency said I should just prepare and leave the food and then walk away. But I said, 'she's not an animal.' I didn't do that. I made her soup and made her eat it. I sat there until she ate it, long after my hours were up; and she did. She wanted someone to talk to her as a human being and to treat her that way; she needed to be told and guided on keeping clean and eating. She had given up; the agency had given up; but not me. You have to talk to them and tell them what's good for them.

I also made her use her hands, for example, picking up plates after eating. I challenge clients. This is good for clients; it makes them feel independent and important. You must let them help themselves, while you supervise. You've got to let them know they're in the world, that they have to do things, that they can do these things.

The ability of a home attendant to win over a difficult client and return the person to what he or she was -- and along the way, to restore dignity -- is the most impressive challenge and accomplishment of the profession. Bringing a client around in this way is sometimes a surprise even to the home attendant herself. "I had one who tried to hit me with a cane. Then she tried to spit on me. I threatened to leave and the client backed off. But, you know, I had that client for 2 ½ years after that! We worked it out." Or, as another put it, "When you first arrive, clients never like the home attendant. Then you try to do your best and they end up liking you."

In some cases, you have to work to overcome a client's fear. Sometimes, recognizing this fear is the key to getting a client to cooperate: "The client is sometimes scared. You have to help him calm down from his fear. You have to understand the fear." Clients may be afraid when you try to move them and may not cooperate for this reason. They may doubt you are strong enough to lift them, or they may question your skills and training. But your own self-confidence is the key, not your size. "The first thing you do is to ask them to be confident in you because you know what you are doing."

How do your get clients to be confident in you? One technique is to make clients partners in their care. "I say, how do you do this? How do you want to help me? How do you want me to help you? Each person has his own way. You can learn from clients."

Physical care for clients often needs to be negotiated. Home attendants have a job to do, but clients may not accept it. They deny they need help and may go to great lengths to pretend they do not. Embarrassment about their frail bodies, or life-long feelings of modesty, make it difficult for many to accept help with toileting or bathing. This adds a psychological challenge to otherwise straightforward attention to physical needs. One home aide described a case this way: "My client is argumentative. He doesn't think he needs help with continence care. We argue and then we come to a good laugh. He just wants to be left alone but he really can't be."

New clients may refuse your help. Remain calm. Remember that it takes time for a client to get to know you and learn to trust you. By saying, "Maybe you'll want to eat later," you give the client a way to have some control. You can still do your job.

Never use force to get a client to do anything. Your actions can be misinterpreted as abusive and you may accidentally injure the client, as happened here:

"Ms. G had advanced Alzheimer's and was in a day program five days a week. One morning she refused to put in her dentures and could not eat breakfast. The home attendant, who had worked with this client for 4 years, was concerned that if she didn't finish breakfast on time, the client would miss the van that brought her to the day care center. The worker dreaded the idea of being left all day with Ms. G, who was extremely confused and agitated. In her panic, the home attendant shoved Ms. G's dentures into her mouth, forced her to eat breakfast, and got her on the van. By the time, Ms. G arrived at the center, her face was badly bruised. The worker was removed from the case."

When a Client Abuses You

"You've got to know when to threaten to leave."

"He was looking for a wife, not a home attendant!"

"There's nothing difficult about being a home attendant, nothing except the difficult client!"

There is no shortage of abusive clients. Every home attendant mentioned at least "one client from hell." Their stories are harrowing. One home attendant was left in an apartment with a drug-abusing grandson who read pornography all day. One faced continual criticism and foul language from the client's husband. Home attendants say the only guideline here is to go to each assignment with an open mind, but also to use the threat of leaving the home as a tool to make the home situation more tolerable. It is also important to contact your supervisor and ask for assistance. When you do contact your supervisor, it is a good idea to send a note, so you have a record of bringing something to her attention. Also, keep a copy of the note for yourself. Remember, your agency is responsible for the client and cannot afford to ignore a problem that is dangerous or abusive to the worker. If you belong to a union, speak to your representative if the agency does not respond to your request for help.

Some clients seek to humiliate home attendants. One home attendant reported that her current client seemed to enjoy criticizing her and blamed her for just about everything. As she put it, "If an orange isn't sweet, she blames me! I can never please her." Others resort to more overt manipulation: "One client would set me up. First, he would call the agency and say I stole money from him. Afterwards, he would say he lied!" These clients often make racial remarks. One home attendant tried to gently chide her client to change this behavior, but to no avail: "She embarrasses me. She is always saying nasty things to people. I try to reason with her, but she tells me to shut up."

Some clients use infirmity or the need for care as a weapon in a battle for authority and control. For example, one client who was able to use the commode near her bed insisted on being taken to the bathroom in the middle of the night. Another used continence care as an occasion to humiliate: "She will pass gas in my face when I'm changing her underwear. She won't wear panty liners; she takes them off and urinates in her underwear, so I have to change her." Another insisted on being bathed in bed when she could easily get up.

In some cases, it may be necessary not just to threaten to leave, but to leave. This leaving can be temporary or permanent. One home attendant described a client, "a very independent man," who ordered her out of the home whenever he got angry. He would yell and she feared that he would wake everyone in the building. So she would leave for about 10 minutes and return when he calmed down.

The abuse may be completely out of control. Still, you cannot simply leave and abandon the client. It can be dangerous if the client is left alone. You should only consider leaving if there is a real risk to your safety. Your agency must know if you are planning to leave. Call. If something happens to the client after you leave, both you and the agency can be sued. You may lose your job and the agency can be put out of business.

When a Family Asks You to Do Things You Shouldn't Have to Do

There are people who think we are maids."

"They want you to cook for them. They want you to serve them. They want you to take care of the whole family, even the dog and the cat."

"I found myself lifting many boxes and I said, 'this is not normal, this is not home care: moving boxes left and right and cleaning out a room."

Clients may feel entitled to make unreasonable demands for care and housework. One home attendant very quickly discovered that her client really wanted someone to get on the floor and scrub the baseboard and then clean the chandelier. The family would leave plates on the tables or in the sink because they knew the home attendant would clean up after them. Another example is the case of the client who went out to play bingo and expected the home attendant to stay home and clean. There are clients who expect home attendants to provide child care, maid service, or even sex. Some expect you to work additional hours for free.

In these cases, you should be guided by the care plan, which is always posted in the home. "Families come in and try to tell you how to do your job and what you are supposed to do and what you are not supposed to do. But what you are supposed to do is follow the care plan." The care plan is your contract with the family. It is important to remember that you work for the agency, not for the family. The care plan is what the agency has determined is appropriate for you to do for the client. If families or clients ask you to do something else, you should remind them of the care plan. If they think the care plan is not right, then they need to call the agency for a re-evaluation of the client's needs and a new care plan.

There is a written client care plan, but there may be areas where responsibility is unclear. A common problem are errands that benefit a household but not necessarily the client, as in this example:

"The worst is when you don't know what to do and you try your best; and then the client turns against you and you have trouble with the agency. It's your word against the client's. One client asked me to do an errand, which I shouldn't have to do. I did it but couldn't be back at her home when I was supposed to be. She complained to the VNS nurse and the agency."

The situation may be complicated by a variety of "deals," in which families agree to release a home attendant from some of her hours or tasks if she agrees to do an errand or housework that is not truly part of her job. Home attendants reported great stress in this area. It can be used against you and lead to loss of a job. Many home attendants said they simply do not consider such offers.

Another problem is pet care. Even pets who are friendly can be a problem. Families may ask you to clean up after a dog, for example. This is not your job and you should explain this from the beginning. Simply being in a home with a variety of pets can be a problem: "One client had 18 or 20 birds and one dog. Last summer, when it was a 100°, she didn't want to open the windows!"

In cases where the client and also the spouse is old and frail, you may find yourself providing help to both. "I feel bad that I cook for the wife only. So I cook for both of them. I feed the husband because the husband is old. When I go to the store, that's for both of them. I am not planning to do everything for him, just to feed him." This can be difficult, since you are assigned to the client only. But if it is not additional work (such as cooking and shopping, which you would do anyway), it may be appropriate. It is not appropriate, however, to let family decide who should be your client.

Also, some clients or families may insist on unreasonable amounts of care. One home attendant reported that a client wanted to be pushed in her wheelchair for six hours. Another insisted that the home attendant go to the store 3 or 4 times each day. The tasks were part of the care plan, but the amount was unreasonable. In such cases, you should speak to clients and families and also the agency.

Finally, families may ask you to perform duties that require medical expertise that you do not have. Administering oxygen or other medical procedures is not part of your job. Even if you have done it in private jobs or for family members, you should **not** take on this responsibility for clients. These tasks require special training; you cannot do them unless you have passed certain tests. A home attendant who agrees to perform medical procedures can get into serious trouble, and so will your agency. If you find that families ask you to perform medical procedures, be sure to inform your supervisor. Remember, if you do this job and something goes wrong, you will be blamed.

When You Feel You Can't Handle the Job but Feel You Can't Give the Job Up

Sometimes conditions in a home or with a particular client are just not acceptable. You can notify the agency and complain, or give up the job. But because of the wait to get a new long-term client assignment, you may be reluctant to complain or leave.

One home attendant reported that she did put up with a terrible home situation, where they would not even let her use the toilet, because she did not feel she could afford to give up the job. Another mentioned that she did not report neglect of the client to the agency for the same reason. She was afraid the agency would call the family, and that the family would dismiss her. As she put it, "You cannot tell them. You have to walk into that house everyday. You don't know what they will do to you."

But other home attendants disagreed. "If you feel the family might threaten you or something, you don't want to be there. You don't go back there." Or, as another said, "I am not going to put myself in that kind of predicament. I will tell the agency that they better take me out of there." Even home attendants who had put up with terrible conditions in the past because they felt they needed a job now agreed that it was not a good strategy. Better to quit the job than face abuse.

One complication, though, is concern for these neglected or abused clients. "If I see something like that, I don't stay on the job but you feel sorry for the client." Still, no one benefits, neither you or the client, if you keep quiet about a situation of neglect or abuse. The welfare of clients requires that you report the problem to the agency. This allows the agency to arrange for the proper intervention.

How do you let the agency know about a problem with a client or home? Using the telephone in the home may be a problem because of privacy. Clients and families may listen in. One solution is to call while you are out doing errands: "When I call the agency to speak to the coordinator, I always try to call when the client sends me to the store. So I call when I am out in the street."

When You Are Bored

"They send you to places where they have the family there, the grandson, the son, the daughter. They are in the house. I ask, if you are here 24/7, why do you need the aide?"

Avoiding isolation and boredom are perhaps the greatest challenges of home care. Many home attendants reported that they do not have enough to do for the 8 or 12 hours they spend with clients. Some live in close quarters with clients 24 hours a day for days at a time, with little or no contact from others.

Some home care attendants add activities to the day and use a schedule to put some structure into the day. In this way, clients and home care attendants have something to look forward to and know what to expect. The schedule might include excursions outside, particular activities (crafts, cooking, exercise), a particular TV show. Activities break up the day. Joining senior center activities can be stimulating to the client.

Other home care attendants mentioned that some degree of boredom is just part of the job. They say that it is important to be with a frail client and that is reward enough:

"You've got to keep people company when they don't have family."

At times, being a home attendant can be very lonely. You can feel isolated, especially if you are assigned to long hours, or do sleep-in work with clients who cannot communicate, or have a client with Alzheimer's disease. For your own well-being, it is important to seek out support and use available resources. The Alzheimer's Association can supply you with literature and guidelines for working with clients who suffer from dementia. At the back of this Manual, you will find other resources you can contact for additional information.

Another way to reduce isolation is to bring your client to a community center or senior program. This might be a way for your client to meet other people and get involved in activities you cannot provide on your own. You might also enjoy seeing new faces. Simply going outside adds some change and variety to the day.

Finally, you should consider sharing your experiences with other home attendants. Perhaps your agency can print a monthly newsletter in which home attendants can send in suggestions or write about their experiences.

When You Need to Call Your Agency

When home attendants and clients or their families have a dispute, the agency is there to arbitrate, to work out a fair solution. This may mean transfer and replacement of the home aide, removal of the home aide for her own protection or safety, additional visits to the home by a nurse or care coordinator, or a change in care plan so that the responsibilities of home aide and client are stated more clearly.

Virtually all the home attendants we spoke to have had to call their agencies about clients or their families. The threat of such a call is an important part of the home attendant "tool kit": "I call the agency when a client curses at me and disrespects me. I did this when one client cursed me. She started to cry and said she was sorry and we got along fine after that."

Of course, the departure of one home aide usually means that another must take her place. Replacing a home aide in such circumstances is difficult. A senior home attendant said she knew she was good at the job when she realized that she could walk into such situations with confidence.

One client called the police. When the police arrived, the client claimed she did not know the home attendant and accused her of stealing. The home attendant explained that she had been working with the client for some time and that the client was confused, but client was agitated and the police recommended that the home attendant leave. The home attendant said, "she is not supposed to stay here by herself. What am I going to leave her by herself? What if something happens to her? I will go downstairs, I will call my agency, and after she calms down, I will come upstairs again." In fact, the client was still agitated when the home attendant returned, so she called the family.

Home attendants reported that clients may not let you come into the house or may even kick you out. "They lock the door, close the door on your face, push you out." In such cases, you need to call the agency.

One way to help avoid these situations is to get involved in making the client's care. When the nurse comes to re-evaluate the client, make sure you are there. You know your client from hands-on experience even better than the nurse. It is your chance to inform the nurse of any behavior or health changes in the client. You can make suggestions for the care plan. This is a good time as well to involve family members. The family may have learned things about their mother or father that can be useful for making the care plan. The family and nurse should be considered your partners in the care of the client.

When You Can't Have a Relationship with a Client

"You've got to give respect to get respect."

"You have to have the patience to deal with sick people. You have to be understanding."

"You have to keep them going."

Aside from Alzheimer's, other psychological problems may interfere with your ability to have a relationship with a client. One home attendant described the difficulty she had with a depressed patient: "My client is depressed. I'm a shoulder to cry on. I say a prayer everyday before I go her house." Aside from the demands of personal care and supervision, the client needed constant reassurance and psychological support. This home attendant spent most of her day counseling the client. She tried to get her to laugh or smile, to keep her busy, and to convince her that she had a reason to live. Most likely, this client needed medical treatment for her depression; in the absence of such treatment, the home attendant was called upon to provide daily counseling.

A change in the client's routine can ward off boredom and feelings of isolation not only for the client but also for home attendants. There are senior centers that take the elderly on trips to the zoo, theater, picnics, and musical events. Sitting in a house with only the television for company can be depressing, bot for you and the client. Look for opportunities in the neighborhood that can enrich the life of your client and give you more to talk about. Even reading stories or the newspaper out loud can be rewarding.

When You See Neglect or Abuse

You may see clients who have been abused or, more likely, neglected. In cases of neglect, families do not provide the food, clothing, medicines, or care these clients need.

"I went in to cover a case and the lady didn't have medicines; her medications were cut off. She didn't have medications for two weeks. There was no food. She looked like she didn't have a decent bath for two weeks. This was neglect, definitely. Whatever money she had, she had to hide it. The children paid no attention to her except to take the money. Even the grandchildren would come in, go right to the fridge, see what there was to eat or drink, and then leave. I called the hospital and social services."

The client neglected by his or her family poses a special challenge. If the family does not provide adequate food, you may be put in an awkward position: "I cannot sit, bring my food and eat it, and not help her when she is so hungry. It's hard. I'm eating and they are looking at me like that." You may be tempted to buy food for the client, but this is not a good idea. It is not part of your job, and if you start buying food you will be expected to continue doing it. Better to call the agency.

When You Don't Speak the Same Language or Share the Same Culture

"I want to tell you something. 80% of the home care workers come from different ethnic and cultural backgrounds than their clients. So we have a difficult task."

"You go into their homes. You have to learn to cook their food, their way. We are all from different cultures and you have to learn cook differently and respect different things."

You may be placed with a client who does not speak the same language as you. Home attendants reported that they had clients (and in some cases families) that only spoke Chinese or Russian, for example. You may have to rely on family to translate or non-verbal communication, such as hand movements. Sometimes, families teach home attendants to speak their language, and other times home attendants teach clients to speak English or Spanish. This can be satisfying.

Some workers who did not speak the same language as the client found it helpful to put labels on important things, in both languages. Labels were placed on medications, doctor's appointment forms, and particular objects in the house.

"It improved my relationship when the client saw that I was interested in communicating with her by learning important words."

When Families Interfere

"Some families get in the way. Even the clients feel that way!"

"Sometimes you have to face the interference from the family."

Families can help, or get in the way and make the job harder, or not be involved at all. The situation becomes more complicated when family are present in the home during home care hours. Home attendants reported that sometimes even clients wished that family members would just let the home attendant do her job, without interfering or trying to supervise. Yet some family members insist on getting involved. In such cases, a difficult job may become even more difficult.

"It's the family that makes it hard. You try to be nice and do your job, but families get in the way."

"My client gets disoriented and then calls her son and daughter. So then I have to deal with her family too!"

These cases may represent normal friction between families, who want what is best for their mother or father, and home attendants, who also want to provide needed personal care. But there are also families with other plans or agendas. These agendas may be mildly abusive, such as seeking extra housekeeping from the home attendant -- for example, leaving the family breakfast dishes for the home attendant to clean. Or the family agendas can be worse, as in the case of one family who sought to pin blame on a home attendant for an adult daughter's own poor judgment in elder care:

"One night my client couldn't sleep, so her daughter gave her a sleeping pill. The client couldn't get up in the morning. The daughter and son were mad and yelled at me. I just did my job and left, but I told the agency."

Families may interfere and not provide the cooperation you need to get the job done. Yet they often depend on you to handle client problems that are too much for them: "The family, when they come, can't stay with the patient long. After one or two hours, they say, 'bye, Mom.' They couldn't be with the patient for 12 or 24 hours the way we do. And they don't provide the cooperation you need. But let me tell you something. When something happens to the patient, you will be the first one they come to. They blame us. It's not right, but it makes you strong inside and outside."

Families may test your honesty. "I had one woman take off her gold ring and stick it inside the drain in the tub. She wanted to see if I would take the ring and keep it when I cleaned the bathtub. I knew she took it off and put it there, because it doesn't come off when she washes her hands. I said, 'Listen, don't play games; take your ring."

Sometimes, even a gift from the family or a client can be a problem. Families want to give gifts but gifts come with strings attached. Small gifts of money, perfume, cosmetics, or chocolates may be a way for families to say thank you. But you should avoid gifts from clients who may have dementia: "One client gave me a nice winter coat. I took it home. The next day she told the agency that I stole her coat. After that I don't take any more presents." It may be hard to keep a professional relationship after you've accepted a gift.

The same is true for private arrangement with families, where they agree to pay additional money if you provide additional services. Experienced home attendants avoid these arrangements. These arrangements only cause trouble. Because it is not part of your work or the care plan, the family can hold this against you. And if the family refuses to pay, you have no rights and no way to hold them to their agreement. Finally, if the agency finds out about such arrangements, you may lose your job.

When Clients Need to Go to the Hospital or Nursing Home

"You have to know what to do in an emergency."

"You have to know what to ignore and what to watch out for."

Home attendants are health monitors. You watch for changes in a client's health. In the case of signs of serious illness, you are expected to call the agency or communicate such information to visiting nurses or doctors. This may not be easy. As one home attendant reported, "You have to know what to ignore and what to watch out for." In some cases, the home attendant's judgment may be better than the client or family's judgment:

"My client fell down a flight of stairs when I wasn't there. Her daughter didn't bring her to the hospital. I called my agency and got a nurse out there as soon as I got to the house and saw what had happened. We got her to the hospital. She had five broken ribs and was bleeding inside. Then another time I noticed a client's stomach was shiny and swollen. I called the doctor. It was her gallbladder."

Many of the home attendants we talked to took their responsibility to monitor clients' health seriously. They wanted to learn more about the typical illnesses they were likely to encounter in clients.

Finally, the home attendants we interviewed were concerned that patients take an active part in caring for themselves. They watch clients' diets ("My client has a blood pressure problem and insists on eating salty food all day!"). They watch a client's weight ('I had one client who was extremely thin. I helped her and she gained weight.") They make sure clients go to doctor's appointments even when clients dig in their heels and refuse to go. They make sure prescriptions are filled and pills taken.

Home attendants come to like and, in some cases, even love their clients. But this is a temporary, fragile relationship. Few home care situations last longer than 2 or 3 years. They end in hospitalization, nursing home placement, or the death of a client. This can be emotionally difficult.

When a Client is Dying

"I would sit with her, message her back, and try to reassure her; but I also left the room to take a break from her moaning and crying. I always came back, though; I just needed to get away for a few minutes. It's hard to listen to someone cry and not be able to do anything about it."

Sometimes you provide end-of-life care for clients. Many of the home attendants we interviewed mentioned that they had seen clients die. Dying is in some cases complicated by pain, which is not always managed well when people die at home. Home attendants reported that listening to the client cry out in pain throughout the day was a great strain.

Death is also a common end to home care. It would be unusual if home attendants did not become attached to clients and did not feel sad when clients die. As one told us, "Four of my clients died. I still cry for some of these good people."

Home attendants can become emotionally attached to a client from years of being together. This is especially true when you like each other and the client considers you one of the family. You may need grief counseling if your client dies while in your care and help with your feelings of mourning and loss. Sometimes a client's death awakens memories of other losses in your life. These can cause deep pain. It might be necessary to take time off from work. If that is not an option, it is best to take a less stressful assignment for a while to give you the opportunity to recover.

How To Make Home Care Satisfying to You, Your Clients, and Their Families

"The job is satisfying when you feel comfortable in the house."

The Good Client

The key to a satisfying home care arrangement is having good clients and good families, so that on the most basic level you feel comfortable in the home. The key to such a good relationship is mutual respect. Courtesy, on all sides, goes a long way.

"To me the ideal client is considerate. One offered me tea. She was nice to me."

"The good clients appreciate what you do. They're easy to work for. They are not overly demanding."

"The ideal client is a client that works with you. Even very debilitated people can help you be a home attendant. Others fight you."

"My client made me feel welcome in her home. She never made me feel dumb or discouraged me."

"The family trusted me and treated me like a person. They trusted me in the house and with money."

"My ideal client? It's one I can laugh with her. It's one where the family thanks me for what I do."

"The ideal client? It's someone who tells you what you did wrong first, so you can fix it, before she tells a family member."

"The ideal client is one who sees you as a person too."

Home attendants recognized that frailty and dementia make it hard, and in some cases impossible, for clients to be "ideal." Most home attendants said they preferred clients who could go outside, participate in conversation, and be a kind of friend. "When you get a client who can talk to you and who you can go out with, that's nice. They feel good and you feel good." At the same time, home attendants recognized that not all clients are capable of doing so. The ones who are a pleasure to be with despite their sickness or frailty stand out, as in this case: "One that sticks out in my mind is a nice man who died. He was very sick, but he joked around and talked with me. He didn't let his sickness get to him."

It's also possible to have an ideal client who is extremely frail. One home attendant reported that her current arrangement worked very well even though the elder was quite impaired.

"My client doesn't get upset. If she does, I can quiet her. I know how to handle her. She's ideal even though she can't move or walk, and I have to do everything. Her daughter is excellent to me. They treat me like family. We work together, so it's easy."

Home attendants also were quick to point out that even the most difficult client sometimes turns out to be not so bad. A rule of thumb is to hold off judging a patient: "They're all unique and after a while you may come to like the client."

Good Families

The best home situation is one where families work with you. Second best are families that do not make the job more difficult than it needs to be. The worst arrangement is actual obstruction or abuse from a family. In our interviews, this last was rare. More common are remarks like this one: "The nice ones stick out in my mind. Like the women whose daughter called me to have lunch. They were nice to me and treated me with respect."

Scheduling Tasks

Apart from cooperative clients and supportive families, one key to maintaining a satisfying home care arrangement is flexibility in scheduling. You need to figure out what a client prefers and, if you can, incorporate client preferences into daily care. This requires that clients and families tell you what the client likes – in bathing, food, how much the client wants to get involved in personal care, and how slow or fast you should work. If you can match your work to a client's preferences, home care is likely to be more satisfying:

"The ideal for me is when you do everything the client likes to do, and you match your schedule to the schedule they like."

"Do what you have to do but try to please them as much as you can."

"Get them to communicate, get them to tell you what they want! Then get the job done!"

Negotiating with Clients

Getting your job done with a minimum of friction requires good negotiating skills. You have to find a way to get your job done that is also acceptable to clients. Home attendants told us they do their job in a way that lets clients feel like they are playing a role, or directing care, even if, in reality, they are not. This is one way to overcome clients' embarrassment and loss of privacy, which, apart from health conditions, may make them resistant to care. But clients have to find a way, with your help, of letting you do your job.

"I had a client who had lived alone for years. Then I came. Eventually she got used to me and accepted me. I told her that she only needed someone to help her, and that I wasn't there to invade her privacy."

"I handle a difficult client this way: I listen to them and see where they're coming from. Then you know how to deal with them. Clients tell me how they want things done; then I tell them how I do things; then we work it out and compromise."

"I had one who didn't want to take a shower. I talked to her and let her do as much as could. I encourage my clients."

"I've had clients who don't want to get up. You can reason with them. Eventually they get up."

"She wouldn't bathe. She didn't want to go out. But I got her to go out. She realized she liked it and then I explained that she wouldn't be able to go out unless she bathed. So we worked it out."

"When they don't want to eat, I tell them they'll get sick if they don't eat and that they'll have to go to the hospital and won't see their families. That does it usually."

Getting the Job Done

Finally, home care aides stressed that clients and families must understand that you have a job to get done. This is the key to a professional relationship, which is required if clients, personal aides, and family are to get along. It is possible to have a professional relationship and personal involvement and affection. But home attendants said they must maintain a professional relationship if they are to get the job done.

"I put my client right in front of me when she's being difficult. We look at each other. I am nice, but I explain I have a job to do."

"The hard clients fight. They don't want to shower or eat, but my job is to bathe and feed them!"

"Getting the job done" may mean working with whatever strengths clients still retain: "I try to make them feel loved. I reason with them. I remind my client of all the things she can still do."

Patience

Patience is the essence of sensitive care.

"You need patience, understanding. You've got to care for the client, be patient, do your assignment, and do it well."

"You have to have patience. You have to like taking care of older people. You have to like being a nurse."

"Follow the rules. Take care of the patient and be patient yourself! You have to be patient to clean a client properly."

Empathy

Empathy, the ability to put yourself in the shoes of your client, is also the key to good care.

"I enjoy taking care of someone. I understand feelings and try to make someone feel better. This makes me feel good. My goal was to be a nurse. This is almost the same field."

"You need to understand clients and leave your own problems at home."

"It helps to be a caring person."

"You need to have a good feeling for people. You are going to see a lot of things."

"You've got to give your love to people, like you would to your own family."

"You need to love elderly people and see that other people don't take advantage of them."

Communication

Patience and empathy make it possible to communicate with clients.

"It's not difficult being an HA. It's how you communicate with clients."

"Nothing is difficult so long as you can communicate with a client. You have to be easygoing and show love You hug them, play some music and dance, hold their hands."

"I ask questions: "Would you like me to whatever?" That helps."

Conclusion

As this guide shows, home attendant care is not always easy or satisfying. Some personal aides report happy situations, such as this one: "My client doesn't want me to leave for the weekend or go on vacation. I quess that means she's satisfied."

But others describe sad situations, unhappy arrangements despite every attempt to communicate: "One wouldn't let me touch her. I never felt comfortable with her." No two clients or home situations will be the same. Still, this manual offers guidelines on what situations you are likely to face and what strategies help you get the job done.

We have presented a picture of home care that is honest, with all its satisfactions and frustrations, and both its success stories and failures. This is what you told us. We have tried to present your story, in your words. We leave it to you to tell us more.