

Guidelines for Initiating Meaningful, Quality Home Visits With People Who Have Alzheimer's Disease and Related Dementia

Wisconsin Department of Health and Family Services
Division of Disability and Elder Services
Bureau of Aging and Long Term Care Resources
1 West Wilson Street PO Box 7859
Madison, WI 53707
608-267-2439
<http://dhfs.wisconsin.gov/aging/Genage/ALZFCGSP.HTM>
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Strategies for Initiating Meaningful, Quality Home Visits with People Who Have Dementia

Table of Contents

Introduction	2
Focus for Thinking About People with Dementia	3
Setting the Stage for Success	4
Communication Strategies: Listening	5
Communication Strategies: Speaking	6
Visits with People in Earlier Stages of Dementia	7
Visits with People in Middle Stages of Dementia	8
Visits with People in Later Stages of Dementia	8

Introduction

The purpose of this guide is to provide strategies for human service professionals conducting assessments and other types of interviews with people who have dementia and reside in the community. This guide was designed to be particularly helpful to people who are meeting with the person who has dementia for the first time, and need to develop an ongoing care management relationship.

This document was initiated as part of a project designed to support care managers in the state of Wisconsin who conduct elder abuse and adult protective services investigations. Under Wisconsin's Federal Administration on Aging Alzheimer's Demonstration Grant activities, the project began in August of 2001. In-depth interviews were done with care managers in nine demographically different areas of the state, who had an average of 18-23 years of experience in adult protective services and elder abuse intervention with people who have dementia. The resulting information was combined with knowledge from best practice care management to produce this guide. Subsequently, the guide has been adapted to support care managers and quality assurance interviewers in all areas of older adult services. This guide was developed By Cathy Kehoe, Alzheimer's Service Developer, Wisconsin Department of Health and Family Services, Division of Disability and Elder Services, Bureau of Aging and Long Term Care Resources.

FOCUS:

Person With **Dementia**

Person with Dementia

Ref: Bradford Dementia Group, Thomas Kitwood Founder, and Author “Dementia “Dementia Reconsidered”.
Open University Press, Buckingham, England; 1997

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Strategies for Initiating Meaningful, Quality Home Visits with People Who Have Dementia

Setting the Stage for Success

1. Get your historic snapshot - Gather as much information ahead of time from key sources about the person's previous and current lifestyle and habits, e.g., routines, eating patterns, work life and schedule, hobbies, personality traits, living arrangements, relationships with family friends and neighbors, etc.
2. Prepare for meaningful time - Bring activities that can easily be shared that are of interest to the person and at the level of their ability.
3. Enlist support – if the person struggles with strangers coming into the home, ask a known person to introduce you. Don't be concerned about communicating who you are to the person with dementia; simply frame your visit as someone who is an interested friend who has come to see them.
4. Attune the environment – Wherever possible interview the person with dementia in his/her own home or room. Familiarity is imperative to a person with dementia feeling safe and comfortable. Be sure that the environment is free from noise, interruptions and distractions; i.e., is quiet, pleasant and calm.
5. Interview the person alone and then with others to gauge if the person is different when with other people. This can give clues about the relationships and issues influencing the person.
6. Prepare to be a mentor to caregivers - Bring information that can be helpful to caregivers in communicating and spending quality time with the person who has dementia. Model effective communication and creative activities, encouraging caregivers to join in.
7. Check your problems at the door – People with dementia, because of their deficits, have heightened sensitivity to other people's moods, feelings, body language and tones of voice. Before interviewing the person with dementia, take a minute to breathe deeply, close your eyes and picture the two of you having relaxed communication with a positive outcome. Enter the person's space as a friend, with a warm smile and relaxed demeanor. The person needs reassurance and understanding in order to communicate with you.
8. Memorize the key questions you want to ask – successful interviews involve a lot of listening with no or little note taking. If you want to conduct questioning from a diagnostic tool such as the Mini Mental Status Exam (MMSE), clock drawing test, etc., try to learn the questions ahead of time so you can work them into the conversation of the interview.

Communication Strategies: Listening

- Show interest and respect by maintaining eye contact and relaxed body language.
- Be calm, patient and don't interrupt; be focused on the present and all of the possibilities that you have to communicate meaningfully right now.
- Read facial expressions and gestures, for they are likely to reveal more than the person's words; gestures may replace forgotten words.
- Enter their world with them. Be an actor in their "play." Remember that whatever they are expressing is actually where they are in time. (Their past is their present, the present is their future, and the future doesn't exist because they can't store memory.)
- Offer comfort and reassurance especially when the person is having difficulty expressing self; offer praise for success in accomplishment (e.g., completing a thought, reciprocating in an activity).
- Offer best guess if you don't understand what is said and the person is becoming agitated. Try again if they say "no" to a guess.
- Avoid criticism, correcting and arguing; this can be traumatic to the person.
- Reminiscence is a key ingredient for success. Do things to initiate fond memories such as humming a favorite song, talking about a pet, offering a familiar photo or object for a story. Smells, taste and touch are also strong memory triggers.
- Engage the person's "body memory" – called the "chaining" technique – to help them initiate or sustain an activity. For example place a glass of water in the hand.
- Use "bridging" technique, a sensory connection that increases focus/attention and decreases anxiety. This could be a touch, a light guide on the elbow to steer, humming, stroking the skin with an object that has a unique surface such as satin. Be sure to ask permission before touching; tell the person what you are doing as you do it.
- Focus on feelings, not facts, and encourage non-verbal communication.
- Confabulating serves to fill gaps in memory. Persons with dementia may make assertions that are not true to cover for memory loss. Trying to argue someone out of such beliefs is usually futile because the person is not lying.
- Refusal to cooperate may be due to sadness, anger, frustration, embarrassment, anxiety. Step back calmly to previous activity and assure the person that he/she is safe.

Communication Strategies: Speaking

- Treat person as an adult and don't be condescending.
- Use short, simple, familiar words and sentences.
- Ignore verbal outbursts if you are unable to respond positively.
- Other forms of communicating include songs, touch, food and joint activity.
- Go to their eye level and be sure that they can see you clearly when you talk and listen.
- Take on a similar posture to theirs to develop rapport non-verbally be on their level.

Remember always that the person before you has had a life rich with history, experience, relationships, skills, hopes and dreams. You are in a position to touch those things within them – however short in time. The connection that you make is not only a bright spot of meaning in their day, it is also a model to motivate others to be creative in their connections with the person as well.

If a person is sleeping or in bed, do not hesitate to ask to have her/him gotten up for your visit. Expect that the visit will be meaningful and that you will gain information that is valuable.

In your role, you may have a wealth of information about this person as he/she declines, and it is important to share this information to keep continuity of care and interests alive for the person. Be sure to inquire into the activities that have had meaning to see if they are still being initiated.

Visits with People in Earlier Stages of Dementia

In people with early stage dementia, deficits may not be apparent until you get to know them. Most at this stage minimize their problem and do not think that they need help.

These people know they have memory problems and have learned how to compensate. Look for lots of reminder notes and routines – everything has its place. Notice if there is a disruption in routine that may be upsetting. You may notice the person acts defensive and pretends not to hear questions.

Work to understand what is behind the behavior – often a fear of someone finding out how bad things are getting, and a subsequent loss of freedom. Be sensitive to this and take things a small step at a time. Also know that loss of control is a big concern. By giving a person with dementia choices and asking opinions, they feel more in control. Above all, let the person know that you are here to help and make things better for them.

Asking questions:

- Keep questions very simple, ones with yes/no or clear answers.
- Work with the person until they have soft facial expressions and smiles, this will tell you that they are comfortable talking with you. At this time start with very short and specific questions.
- If a person begins to move away from questions – such as giving answers that don't make sense, suddenly changing the subject, and tensing body language – go back to building rapport before asking about anything else.
- Build questions into the interview that give you the information you need. Ask questions that test long-term memory, short-term recall and show attention span (e.g., ask them to get you a drink of water).
- Is this person a good historian? Are they being socially appropriate in their responses to others?
- Insert MMSE and other “diagnostic” questions into the conversation. If you want to do clock drawing give them paper to doodle on while you're talking so that you could naturally lead into asking them to draw a clock.
- Avoid leading questions that give the answers such as “you're having a good day today aren't you?” This tells you nothing because the person is likely to agree with anything you say.
- Ask questions more than once to assure answers are consistent.
- When interviewing ask about significant people such as who is the landlord or main caregiver. Ask men historical and current questions about the politics – the president/governor, etc., and sports.
- Red flags in answering questions: Covering up for memory problems by dodging the questions with jokes or sidetracks, controlling the conversation, confabulation, talking only about topics they know well, word searching for “whatchamacallit.”
- Recognize change in capacity as normal fluctuations related to the disease.
- Do not assume because of difficulty communicating that the person with dementia has lost insight or does not understand.

Meaningful Visits with People in Middle Stages of Dementia

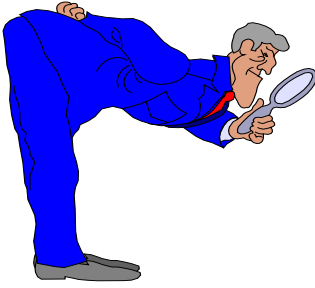
People in mid stage dementia have usually lost insight into their situation.

- Enter their world. They may be talking about another time or place, go with it and ask where they are, what they are doing. Let them take the lead and you follow. Listen to the themes behind what they are saying – this will tell you what their underlying concern is.
- Allow their behavior and confusion to communicate needs that they can no longer express directly.
- **Observation** is much more critical – body language will tell you a lot. If a person pulls away suddenly or jumps when someone comes in the room it can indicate mistreatment, fear, uncertainty, anxiety.
- You may need to use props/familiar objects to communicate such as asking what a person in a picture (a relative) would say about the person right now. You may try different approaches to questions such as “If a friend of yours were in a situation (describe the situation the person with dementia is in) what would ... (s/he feel like, you advise them to do? etc.)
- Behavior at this stage is their means of communication. Acting out can indicate frustration, boredom, pain, anxiety or hunger. It is not being done on purpose to upset someone.
- People at this stage have a lot of energy. They need to pace, arrange and rearrange objects, concentrate on short and likely repetitive tasks. Allow high energy people to pace, arrange and rearrange objects, concentrate on short and likely repetitive tasks while you talk with them. Ask them about what they are doing and why. Be careful about getting too close physically because this could cause anxiety and outbursts. If you want to enter their space, ask permission first and go very slowly. Be ready to pull back if it causes anxiety.

Meaningful Visits With People in Later Stages of Dementia

- Observations are most critical in this stage of dementia.
- People in later stage dementia tend not to recognize most people, even family members. Cognitive and functional capacities result in orientation to self and they tend to treat everyone with a pleasant demeanor and be overly grateful for help.
- At times it may be hard to get them to respond because they lapse into periods where they seem to be asleep.
- Verbal communication is limited to sounds and simple words, short phrases and songs may be repeated often.
- Caring touch is the primary sensory mechanism for interacting with others. Through caring touch, the messages received by the person with dementia should include compassion and connectedness. Through caring touch and talking with the person, s/he can be coaxed into communication.

Principles for Success – Getting People to Accept Help



Person with Dementia

1. Decode the message they're sending.

What is the common theme behind their behavior?

How can you tie the services/interventions into the person's desires?

2. Who is the person? How can we enter their world?

What interests, hobbies, volunteer activities, clubs, etc. have they participated in?

How can you tap into the remnants of these to introduce new things?

3. Routine is security.

How can you build things into existing routine?

How can you introduce things so that they can become routine?

4. Work from the familiar.

Who in this person's life do they trust?

Who lives nearby?

Who has been a part of their routine (congregation, stores, neighborhood, etc.) ?

Which trusted person is available and willing to introduce new things?

5. Know your resources.

Are there services that come to the person (doctors, evaluators, nurses, etc.)

What options and services are there specifically for people with dementia?

What resources does the dementia specialist in your county know of?

What resources does the local Alzheimer's Association Chapter know of?

6. Take small steps, build trust, and plan to have many tries at things before they become familiar.

Is there a way to start something as a "social visit" to try it out with a trusted escort?

Have a good plan that is shared with all involved.

7. Remember to reassure their fears of losing control of their life.

Give control to the person wherever possible through choices, opinions, being involved in decision making, etc.