



## DEMENTIA CARE SERIES

Michigan Department of Community Health

THOUGHTS & SUGGESTIONS FOR CARING

# Caring Sheet #10: Communicating with Health Care Providers

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## Introduction

This caring sheet gives suggestions for families regarding effective communication with physicians, nurses and direct care providers.

Family caregivers sometimes express frustration with the challenges of communicating with health care providers, particularly physicians, nurses, and direct caregivers who staff residential, home health, or adult day programs and physicians' offices in the community. Consistent reliable communication between family caregivers and health care providers requires sensitivity, flexibility, and empathy.

There may be differences between family caregivers' expectations and those of the health care providers. Families might be frustrated over the lack of detailed knowledge health care providers have about their loved ones and the frequency with which they have to repeat requests or information. Health care providers might experience frustration over families' unrealistic expectations of care providers or of their loved one. They may believe the families' complaints about care providers reflect denial, grief, or guilt, rather than justified criticism.

Interactions between health care providers and families that are potentially most frustrating occur during the time of diagnosis, during a medical or behavioral crisis, or when a family is considering a move to or within a residential setting. All of these times are highly stressful for families. Frequently the health care system does not provide enough support and information or sufficiently address families' questions and anxieties.



## Physicians:

- **Summary of purpose and specific issues:** Summarize for the physician the purpose of the visit or phone call and what specific areas need to be addressed. Generally caregivers will have approximately 15 to 20 minutes of contact with the physician during a routine examination. Provide any written summary documentation from other physicians, specialists or additional health care providers to contribute to the medical history. Provide a list of current medications at each appointment and inform the physician of any over-the-counter medication use. Take notes during the visit.
- **Details of symptoms:** When describing symptoms or behaviors it is important to say when the symptoms began; if the symptoms have been on-going; and whether the symptoms have changed in frequency, intensity, duration, or in any other way. Identify interventions that have been effective and those that have not been effective.
- **Goals:** It is important to clearly describe any expectations or goals for the appointment or for the treatment. Examples of goals might be additional information, a change in treatment plan, a routine check up, seven hours of sleep a night (for the person with dementia or for the family caregiver), or a referral to another health care provider. It may be helpful to ask the physician if these goals or expectations are realistic and what the physician has set as treatment goals.

## Nurses:

- **Accessibility:** Most physicians rely heavily on the support of nursing staff, and assume the nurse's primary responsibility is to prioritize information and cases for physicians. Frequently, nurses address caregiver concerns or issues directly over the phone or in person.



Large practices may also utilize nurse practitioners. Nurse practitioners can write prescriptions for many medications and are usually more accessible than physicians. Nurses are usually able to devote time to gathering detailed information about a person's medical history and can summarize and document the information for the physician.

- **Direct Care:** Depending upon the situation, nurses can often directly and effectively address caregivers' concerns in a more timely fashion than can the physician. They may be able to help problem solve a difficult behavior. They can usually refer caregivers to other support resources within the community or residential setting. It is important to follow the suggestions listed above under "Physicians" when consulting with the nurse.
- **Disagreement:** Because a major part of the nurse's role is to prioritize issues and cases for the physician, the nurse may determine that a particular issue is less urgent than the caregiver believes it to be. When this happens, it is important for caregivers to try to discern whether the situation is truly urgent or if it simply feels urgent. An example might be a sudden change in behavior that the nurse believes, based on the details provided, may be caused by a urinary tract infection (UTI). Diagnosis and treatment of a UTI requires lab tests and a prescription of antibiotics, all of which can usually occur without direct contact between the caregiver and physician. While the change in behavior may be viewed as an urgent problem by the caregiver, the nurse may see it as a frequent and relatively routine problem that can be easily diagnosed and treated. If the caregiver strongly wants more contact with the physician or if there are recurrent concerns that need attention, it is important to clearly communicate such desires and concerns to the nurse.



## Direct Care Providers:

- **Loving, Caring Relationship:** Those health care providers who provide direct care, such as escorts, volunteers, home health assistants, and caregiving staff in residential settings develop a close, often loving relationship with a person with dementia that is quite different from the family's relationship and history with that same person. The relationship between the direct care provider and a family's loved one can be hastened and enhanced by sharing with the direct care provider the history (what was the person like before the dementia?) and personal life style or coping style of the person, as well as the idiosyncrasies (such as times of day when the person is most able to perform certain tasks) and interventions that seem to work. This information can help the direct care provider better understand the behavior of the person with dementia, as well as the perspective of the family.
- **Share History:** Create a photo album or wall story board with labels and details that can be hung in the person's living space. Care providers can use these as an activity or conversation trigger with the person. Photos can be copied easily to avoid the risk of loss or damage to the originals, and can be organized by topic or chronologically. Write a brief history of the person, including favorite memories of family vacations, travel, holidays, important dates and events. Personalize the person's living space using family photos, items from hobbies or pictures of pets. If the person is living in a long-term care residence, label these items with the person's name.
- **Visits and Phone Calls:** Give care providers a one page list of family and friends who might visit, call or write so the care provider can assist the person more easily. Place the sheet in the person's records, as well as in the living space where it can be easily located, such as inside a



closet door. A person with dementia might frequently ask care providers where loved ones are or when they will be there. Give care providers written instructions that outline how to assist the person with using the telephone. Give parameters, such as “Call between 7:00 pm and 9:00 pm. It is okay to call at work for non-emergency calls. Limit calls to once a day”. Establish a calendar for visits. This can be posted in the person’s living space and help care providers know when the family will be there and how to respond to questions about visits. Ask all visitors to record their visits so the family will know who has come to see the person. Monitor the visits and phone calls and tell care providers when the visiting schedule seems too exhausting or needs to change for any reason. The care providers may be able to suggest appropriate times and frequency of visits.

- **Keeping in Touch:** Many times it is the accumulation of seemingly little things that create tension. When addressed immediately, the little annoyances can be resolved and the comfortable relationship between care providers and family preserved. These annoyances or concerns might include missing items, particular words the care provider uses, or how the person with dementia spends time. Try to establish a consistent routine of checking in with care providers on a regular basis. Keep a journal or log in the person’s living space as a method of communication with care providers. Care providers might use the log, for example, to let the family know about additional clothing or toiletry needs or what the person did that day. Clarify who should be contacted regarding a particular issue or concern. Concerns about care issues are usually best addressed face to face with the responsible care provider immediately. Be sure the care provider accepts responsibility for following through with the issue.



## **Know the System**

During the course of a person's dementia, there will likely be a variety of health or care systems (such as, outpatient clinics, hospitals, nursing homes, assisted living residences, day programs, visiting nurses or home health) participating in the care of the person. It is important to gain as much information and familiarity with the system as possible, as soon as possible. Knowing whom to talk to when, and about what issues or questions, is crucial to the efficient and comfortable use of the system.

The care providers who work within the health or care system are also people who need support and who operate most effectively in certain settings and during certain times of day. Ask each person when is the best time to talk and to resolve concerns. Ask also what kind of help the care provider would like while providing care for the person with dementia.

Each system has its own way of handling disagreements between the care provider and the family. When sufficient rapport has been established, ask about how disagreements are addressed. Ask who should be called when disagreements arise.

There are times when the family has more experience or information about dementia than the care providers have. (Perhaps the family has recently attended a conference and received updated information that the physician or direct care providers have not yet heard about.) Tactfully sharing pamphlets, newsletters, and news releases from the Alzheimer's Association or other organizations may be helpful. It is also frequently important to get a second opinion, to get a referral to a specialist, or to request a lengthier visit to discuss in detail concerns or information. Learning about dementia in general and knowing alternative care options in the geographical area are important assets.

As a care provider and a person with dementia come to know and trust each other, they will develop a bond that is separate from the family, and is crucial to sensitive, insightful interaction and decision making. The care providers will learn many details about the loved one with dementia and about her or his strengths and needs that will be invaluable. Trust between



the care provider and the family is crucial, as well as respect for the unique relationship and love each care provider and family member has with the person with dementia.

As this trust and mutual respect between the care provider and family grows, loving and caring for the person with dementia can be a partnership and source of strength and gratifying comfort to everyone involved, including the person with dementia.

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