

# Care Partner Information

## *Alzheimer's Disease and Related Dementia Caregiving Tips*

### HIPAA Privacy Rules

#### What is HIPAA?

A person's health information is private. Doctors, nurses and others in health care can only discuss health matters with those who have a medical "need to know." They can't even tell a person's family members unless they have permission from the patient. Only if a person agrees can this information be shared.

A law called HIPAA (Health Insurance Portability and Accountability Act) sets these rules. HIPAA gives patients the right to see their own medical records, and lets patients decide who else can see them.

HIPAA protects patient's health records from getting into the wrong hands. Information that cannot not be shared, unless the patient allows it, includes:

- Diagnosis (what is wrong with the person)
- Prognosis (what is likely to happen to the person)
- Exam results
- Blood test and x-ray results
- What medicine a person is taking
- Hospital records and office records, including electronic records

#### What HIPAA Means for Care Providers

HIPAA is important because it protects patient privacy. But it can also be frustrating for care partners who are helping with care of a person with dementia. They may want to know how the dementia is doing. They may want to know what medicine the person is taking, or how the medicine should be taken. They may want to know what side effects to look for. Doctors and nurses can share this information with care partners, but only if the patient says they can.

This Care Partner Information page is part of a series on caregiving tips. They are written to help family and community caregivers, direct care workers and community health representatives care for someone with Alzheimer's disease or other types of dementia. Available in English and Spanish at [www.aging.arizona.edu](http://www.aging.arizona.edu)

## Care Partner Information

### Getting Permission to Share Information

Special paperwork and forms are needed to give doctors, nurses, and hospitals permission to share information. You can get this paperwork from your doctor or the hospital. It is best to have this paperwork completed and on file before a person's dementia gets so bad that they can't give permission. The paperwork should be copied and given to doctors, pharmacies, and hospitals. Family members and other care partners should keep copies.

### What Happens if the Person Can't Give Permission?

It is best to deal with HIPAA permission before dementia gets so bad that the person can't make decisions. But, sometimes families wait too long and the dementia gets worse. Then when permission is needed, the patient can't understand enough to give permission. In that case, sometimes a doctor or nurse can share information with a care partner if they decide it is in the best interest of the patient. Other times, it may be necessary to go to court to have a judge give permission. If you do have trouble getting the information you need, start by talking to a social worker or patient representative at the clinic or health plan.

### Important Facts About HIPAA

- Don't assume family members or friends have the right to know. They need special permission.
- Decide who should get that permission to obtain medical information. Decide early on, before dementia gets worse.
- Review HIPAA paperwork at least once per year. Review more often if situations change.
- Assure that your doctors, pharmacy, and hospital have copies of the paperwork.

Remember, communication between a person and their health care providers is private. Health care providers have a responsibility to only discuss health matters with those who have a medical "need to know."

### Useful Websites

HIPAA: Questions and Answers for Family Caregivers

[http://www.nextstepincare.org/uploads/File/NSIC\\_HIPAA\\_4.24.pdf](http://www.nextstepincare.org/uploads/File/NSIC_HIPAA_4.24.pdf)

Written by: Jane Mohler, NP-c, MPH, PhD, and Lisa O'Neill, MPH, University of Arizona Center on Aging

Alzheimer's disease and Related Dementia ~ Care Partner Information

Edited by an interprofessional team from the University of Arizona Center on Aging,  
Alzheimer's Association - Desert Southwest Chapter and Community Caregivers

This project was supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number UB4HP19047, Arizona Geriatric Education Center. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.