

alzheimer's  association®
Midlands Chapter

1941 South 42nd Street, Suite 205

Omaha, NE 68105



Ethics

&

ALZHEIMER'S DISEASE



alzheimer's  association®
Midlands Chapter

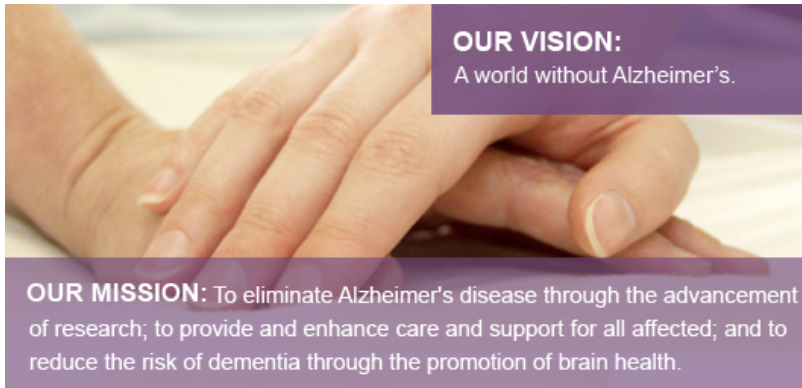
Headquarters Office
1941 South 42nd Street, Suite 205
Omaha, NE 68105
Business Phone: 402.502.4301
Fax: 402.502.7001

**We're here to help and offer hope.
All day. Every day.**

24/7 Helpline: 800.272.3900
www.alz.org/midlands

ABOUT THE ALZHEIMER'S ASSOCIATION® MIDLANDS CHAPTER

The Midlands Chapter is a not-for-profit organization founded in 1982. The Chapter is comprised of volunteers, lay persons, and healthcare professionals committed to working together to accomplish the Chapter's mission.



OUR VISION:
A world without Alzheimer's.

OUR MISSION: To eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

alzheimer's association® Midlands Chapter

Headquarters Office
1941 South 42nd Street, Suite 205
Omaha, NE 68105
Phone: 402.502.4301
Business Phone: 402.502.4301
Fax: 402.502.7001


Branch Office
Charles E. Lakin Human Services Campus
705 North 16th Street
Council Bluffs, IA 51501
Business Phone: 712.322.8840
Fax: 402.502.7001

**We're here to help and offer hope.
All day. Every day.**

24/7 Helpline: 800.272.3900
www.alz.org/midlands

BROCHURES AVAILABLE THROUGH THE CHAPTER OFFICE

Below is a list of brochures that can be obtained by contacting the Chapter office. Please check the brochures you would be interested in receiving.

- Activities for the Person with Alzheimer's
- Alternative Living Environments for Individuals with Dementia
- Alzheimer's Disease Early Stage Support Group
- Late Stage Care
- Caregiver Stress—Signs to Watch for...Steps to Take
- Communication Tips for Caregivers of Individuals with Alzheimer's Disease
- Driving and the Individual with Alzheimer's
- 50 Things You Should Know about Alzheimer's Disease
- Iowa Spousal Impoverishment-Designation of Resources
- Nebraska Spousal Impoverishment-Designation of Resources
-  Program
- Selecting a Dementia Care Unit
- Sleeping Through the Night
- 10 Warning Signs of Alzheimer's Disease
- 10 Ways to Help Alzheimer's Families
- Early On-Set Alzheimer's Disease

ADDITIONAL INFORMATION AVAILABLE

- Copy of the Chapter's e-Newsletter *(Must have e-mail address to receive.)*
- Information on Current Research

Name: _____
Address: _____
City: _____ State: _____
Zip: _____ County: _____
Phone: _____ E-Mail: _____

Please mail this form to:

alzheimer's association®
Midlands Chapter
Headquarters Office
1941 South 42nd Street, Suite 205
Omaha, NE 68105

CREATING COMMUNITY AWARENESS SHARING OUR STORY & ADDRESSING THE ISSUE

The concerns, needs and hopes of the individuals and families affected by Alzheimer's disease and related dementias must be shared to strengthen the support of the communities that stand by us.

The Alzheimer's Association® believes that together we can accomplish this through expanding our Iowa and Nebraska Community Awareness Network.

Community awareness takes on many different forms of communication with several diverse audiences who need to hear from us. Your participation is essential for our success.

Why should I get involved?

- To increase funding to find a cause and cure for Alzheimer's disease.
- To establish a fair system of financing long-term care.
- To build strong organizations that can ensure elderly concerns are addressed appropriately both by government and your community.
- To make improvements in individuals' lives.

Only if we address the issues will we influence the solutions. Advocating for legislation and public policy issues through letter writing and direct contact with elected officials is critical.

The Chapter creates awareness by informing the public and sharing experiences whenever possible. Please consider becoming a part of the Chapter's Advocacy Network.



INFORMED CONSENT / COLLABORATIVE DECISION MAKING

The delivery of contemporary health care is characterized by an emphasis on the role of individuals in making decisions about their care and treatment. Decision making in health care is a process based on a relationship between the individual with the disease and the health professional. The framework encourages communication among all involved: the individual with the disease, health care professional and family or guardian. This brochure is designed to help you with decision making whether you are involved in a decision about discontinuing life-sustaining treatment or how to proceed with a certain procedure or medication.

Regardless of the type of decision, the individual has the right to make decisions. Fundamental to the decision making process is informed consent. Informed consent means that a competent individual understands: the nature and extent of his/her illness; the proposed intervention; alternatives, including non-treatment; and the risks, disadvantages and advantages of each. This information is usually presented by the physician and supported by the health care team in non-technical, understandable language.

If the individual is unable to participate in the decision making process, which is often the case in Alzheimer's disease, provisions should be made for a substitute decision-maker, that is, a person who has the authority to make decisions on behalf of the individual. The courts have established the order in which others can act: spouse, eldest child, parent, sibling, or guardian. The individual, while still competent, may name the substitute (surrogate) decision-maker through an advance directive (durable power of attorney for medical treatment) or through judicial proceedings that result in the appointment of a legal guardian. The substitute decision-maker is presumed to be the one who is best able to represent the interests of the individual with the disease and make decisions that are consistent with the individual's wishes and life plans. The task is to determine what the "individual would have wanted" in the absence of advance directives. All of the standards of informed consent previously described for individuals apply equally to substitute decision-makers.

Sometimes, even with a degree of incapacity, an individual still possesses the ability to participate in decisions about medical treatments. Thus, unless an individual clearly lacks decision making ability, it is best to involve the individual in the decision making process to whatever degree is possible. Open discussions with all involved offers the opportunity to clarify treatment goals, acknowledge the seriousness of the prognosis and realistically deal with potential problems.

The term "individual" refers to the person with the disease.
The term "substitute decision-maker" refers to the person appointed to make a decision.

Written by Amy Haddad, RN, MSN, PhD-Proffesor of Health Policy and Ethics-Creighton University-Omaha, NE.

DISCLOSING THE DIAGNOSIS

Disclosing the diagnosis early in the disease process allows the individual to continue to have an optimal quality of life and take an active role in planning his/her future. If disclosure of the diagnosis is made after the dementia has advanced, participation in planning may no longer be warranted or meaningful for the individual.

If the individual is informed of the diagnosis early, he/she can be involved in communicating and planning for end-of-life decisions. These plans can apply to issues such as life-prolonging measures and consenting to participate in Alzheimer's research. These wishes/decisions can be expressed through legal documents called advance directives.

A joint meeting with the individual and the family members should be arranged to disclose the diagnosis. The initial meeting can be overwhelming; therefore, a follow-up meeting to continue discussion of the diagnosis and available support services may be needed.

Consider the following before communicating the diagnosis:

- Understand the family dynamics and cultural values.
- Include all of the professionals (nurses, social workers, psychologists, etc.) involved in determining the diagnosis in a joint meeting to answer questions, provide specific recommendations and allow sufficient time to answer questions from the family.
- Discuss how the disease might progress and agree upon a specific care plan that considers the individual's values and beliefs.
- Schedule a follow-up meeting, if needed.
- Provide **written educational information** and a list of available community resources.



PAIN AND THE INDIVIDUAL WITH ALZHEIMER'S DISEASE

Q. What medicines can be used for the treatment of pain?

A. Medications used for pain include aspirin, acetaminophen (Tylenol), and non-opiate medications collectively referred to as NSAIDs (non-steroidal anti-inflammatory drugs). Examples of NSAID's are Ibuprofen (Motrin, Advil) and many others. The primary therapeutic tool for the management of moderate to severe pain is opiate medication. Examples of opiate medicines are codeine, morphine, oxycodone and fentanyl.

Q. What is the biggest problem in treating pain in individuals with Alzheimer's disease?

A. The single biggest problem in treating pain in individuals with or without Alzheimer's disease (AD) is our society's reluctance to use prescription medication for the treatment of pain, especially for chronic pain. This reluctance reaches almost insurmountable proportions when the medication prescribed by a physician is an opiate. Opiates are legally defined as controlled substances and are referred to by many as narcotics.

Q. If these medicines are used, won't the individuals become addicts?

A. This common perception rarely becomes reality. Pain specialists have proven that the risk of addictive behavior in individuals, without pre-existing psychological problems, is extremely rare. In the context of treating an individual with AD, it is of no concern.

Q. How often should I give pain medicine to my loved one with Alzheimer's disease?

A. Chronic pain is usually treated with medicine around the clock; acute pain is related when the individual complains of pain. Some acute pains are treated on a schedule for several days. It is important that you not alter the medication schedule your physician prescribed.

Q. My loved one can no longer communicate effectively. How can I tell if she/he is in pain?

A. Recent research has shown that complaints of pain in cognitively impaired individuals are valid. The most important thing is to believe the individual. If they behave like they did when they complained of pain before they became non-communicative, then give them medicine. We often have non-verbal (not able to speak) actions that accompany verbal complaints. When we become non-verbal, those physical actions do not change significantly.

HOSPICE CARE

During the terminal stage of Alzheimer's disease (AD), hospice care can be particularly beneficial to individuals with AD and their family members. Hospice, which is normally offered to individuals expected to live less than six months, includes comprehensive palliative care* and support services, including bereavement counseling for family members.

Aggressive life-sustaining treatments such as artificial nutrition and hydration, antibiotics and cardiopulmonary resuscitation are not normally recommended for individuals using hospice care. It is important to assess the individual's need for pain control, since many individuals with AD may be unable to verbally communicate their discomfort.

Medicare, Medicaid and many private insurance companies have hospice care benefits. Many individuals on hospice care are in the home while some may be in long-term care settings.

Despite these benefits for the individuals with AD and their families, few take advantage of hospice care. Physicians, health care professionals and families can change this trend by generating information on the benefits of hospice care for individuals in the terminal stage of AD.

**attending to the physical comforts of the individual with the disease*



ADVANCE DIRECTIVES

Every state now legally recognizes advance directives. The two common forms of advance directives are a living will and a durable power of attorney for health care. A living will states the individual's choices for future medical care decisions. When individuals are no longer able to make these decisions, a durable power of attorney allows the individual to designate a substitute decision maker, usually a trusted family member or friend, to make specific treatment decisions for them. The substitute decision maker should make decisions consistent with what he/she thinks the individual's wishes would have been. In the absence of written advance directives, care providers and substitute decision makers should try to learn about the individual's wishes from family members as a basis for making these decisions.

Both the living will and durable power of attorney must be drawn up while the individual issuing the documents is considered legally competent.

Adapted from "Fairhill Guidelines on Ethics of the Care of People with Alzheimer's Disease: A Clinical Study," prepared by Stephen Post, PhD and Peter J. Whitehouse, MD, PhD.

TREATMENT WITHDRAWAL/REFUSAL

If there is an identified substitute decision maker, that person should be contacted and involved in the decision making process. The substitute decision maker should work closely with the family in cases where a substitute judgment must be made to follow the advance directive. If there is a lack of knowledge about the individual, the substitute decision maker should base a decision on what he/she thinks is in the best interest of that individual. If necessary, the importance of respecting the individual's wishes should be clarified for the family. Clinical ethics consultants or facility's ethics committees may offer assistance in arriving at a mutually agreeable decision.

An individual's right to refuse or withdraw any treatment, including treatment for life-threatening illness (infections, hemorrhaging, heart attacks, etc.), is not the same as assisted suicide or euthanasia. In fact, aggressive medical treatment may seem cruel to the individual because of his/her lack of orientation to the surroundings and understanding of the intentions of care providers.

Adapted from "Fairhill Guidelines on Ethics of the Care of People with Alzheimer's Disease: A Clinical Study," prepared by Stephen Post, PhD and Peter J. Whitehouse, MD, PhD.

ETHICS IN RESEARCH IN ALZHEIMER'S DISEASE:

There are many ethical quandaries involved in research about Alzheimer's disease (AD). These include areas as diverse as the implication of genetic testing, the implications of proposed treatments for AD and, more fundamentally, the participation of individuals with AD in clinical research studies. There has been increased interest nationally in the conduct of research studies which involve the participation of persons who have brain diseases such as dementia or schizophrenia. A concern has been the ability of such individuals to agree to participate in research studies when their illness may affect their ability to reason and make sound judgments. Several groups have felt that the rights of such individuals have not been adequately protected particularly in some types of research about schizophrenia.

When an individual first considers participating in a research study, the initial task is learning the purpose of the study and what will happen during the study. In a study which tests a new drug treatment, this would entail learning what drug will be investigated, what the potential risks and benefits of taking the drug are and how the person will be monitored during the study. After this information is presented, the individual is asked to give his/her permission to participate in the study. This presentation of information is usually given in the form of a written document called a "consent form" which the individual is asked to read and indicate that he/she understands the document by signing it.

A critical issue for individuals with AD is that they may not be able to fully comprehend this often complicated document, or, if they fully grasp it at the start of the study, may not have the same level of understanding by the end of the study. How then can such a person give meaningful consent to participate?

GUARDING THE RIGHTS OF INDIVIDUALS WHO CHOOSE TO PARTICIPATE IN RESEARCH STUDIES

There is no simple answer to this, but one approach is to ask the potential study participant to sign a brief simple "assent" form to indicate that they know they are participating in a research project. Participants can also designate an individual who will serve as their "durable power of attorney" for the study.

In brief, the individual with AD identifies someone, usually a spouse or child, to whom he/she gives legal permission to oversee his/her participation in the research study. This designee has the right and obligation to decide whether the individual should participate and serves to protect his/her interests throughout the study. This seems a bit complicated but can be considered a happy medium between the interests of the researcher and the rights of the individual.

Research is an absolute necessity if we are to come to a better understanding of AD and develop better treatments. It is also imperative that the rights of the individual are fully protected in this process.

Written by William J. Burke, MD-Professor at the University of Nebraska in Omaha, NE. He is also director of research for the department and director of the Division of Geriatric Psychiatry. Copyright © 1998, William J. Burke, M.D.