Therapeutic Goals

COMMON QUESTIONS

■ What issues should patients and families consider when making decisions about the use of prescription medications to treat Alzheimer's disease?

■ If a particular treatment for Alzheimer's exists, are families ethically obligated to make sure the patient receives that treatment?

BACKGROUND INFORMATION

Current pharmaceutical treatments prescribed for people with Alzheimer's disease may improve cognitive functions, such as memory and reasoning, or modify behaviors, such as aggression or delusions. Research on new therapies focuses not only on treating these symptoms but also on slowing progression of the disease.

ASSOCIATION POSITIONS

The Alzheimer's Association Ethics Advisory Panel heard a detailed presentation in December 1997 from Steven DeKosky, M D, chair of the Association's Medical and Scientific Advisory Council, regarding research on new therapies and the ethical aspects of therapeutic goals. The panel concluded that it is important for consumers to consider the goals of various therapies, especially as new treatments are being developed. Patients and families should consider whether the medication is proving effective, whether it is improving quality of life for the person with Alzheimer's, whether it is making the task of providing care easier or more difficult, and whether it should be applied in all stages of Alzheimer's. Physicians should be attentive to questions of therapeutic goals and consider the withdrawal of treatments based on perceptions by family members that burdens outweigh benefits. Several questions are worthy of consideration by professionals, family members, and people with Alzheimer's in the highly personal decisions about therapeutic goals.

With regard to cognitive enhancement, the following questions are important:

1. To what extent have diagnosed persons and their family members placed hope in medications, and are these hopes realistic?
2. What is the perception of the diagnosed person and their family members regarding the effects—positive and negative—of these compounds?
3. If the compound slightly improves cognition but lowers quality of life or complicates caregiving, is it worth using?
4. What are the patient's or family's therapeutic goals, and how long do they wish to use the compound?
5. What should professionals tell patients and their families about the usefulness of these medications and about the value of use in various stages of Alzheimer's?

With regard to slowing progression, the following questions should be considered:

1. What does the caregiver or person with Alzheimer's think is meant by "slowing progression of disease"?
2. At what stage in the disease would the use of such a compound be most beneficial?
3. Is there any stage in the disease when slowing the progression would be unacceptable?
4. How do you balance the values of extended life and quality of life?
5. Would you use such a medication to keep a loved one home longer, rather than in a nursing home?

It is important that, as new drugs are studied and approved in the future, those engaged in the care of Alzheimer patients reflect critically on the ethics of therapeutic goals.

Important considerations: When new treatments come on the market, there may be subtle forces on families to be sure their loved one receives the treatment. These forces are increased by “direct-to-consumer marketing” practices of pharmaceutical companies and by cultural norms which create expectations, even a moral obligation, that any and all treatments must be tried. Nonetheless, individuals always retain the right to refuse any treatment. And by extension, if they are not capable of expressing their views, their surrogate decision maker retains this same right.

To receive additional Association materials on this topic, log onto the Association’s Web site (http://www.alz.org) or call (800) 272-3900.