

Toolbox: A shared decision-making guide for antipsychotic use in dementia

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Decisions to use antipsychotics for people with dementia are often challenging and complex. These drugs have a black box warning for use in dementia since their use has been associated with increased mortality.¹ They can cause other harmful side effects, and their efficacy is limited.¹ This has led some to believe they should never be used in dementia, but many clinicians still feel antipsychotics can be appropriate treatment for severe symptoms when alternative management strategies have been unsuccessful. Potentially appropriate indications include behaviors that threaten the safety of the patient or others, or troublesome symptoms that have a significant negative impact on the patient's quality of life or ability to receive needed care.² As with any medical treatment, especially those with the potential to cause severe adverse outcomes, we believe it is important for patients and families to be informed of the risks and benefits and participate in treatment decisions whenever possible. This belief is based ultimately on the principles of personal freedom and choice that are the foundations of a free society, also known as autonomy.³ Involving patients or family decision-makers in making informed choices may also reduce the chance that litigation will result if an adverse outcome occurs when a person is receiving an antipsychotic, though formal evidence is lacking on this topic.⁴ Shared decision-making does not preclude a provider's expression of an opinion about the best treatment option, but it does include a responsibility that the provider justifies this option to patients or families, informs them of alternatives, and gets their agreement. This is not so different from informed consent.³

Shared decision-making is increasingly being recognized as an important part of patient-centered care, though research suggests provider-patient communication is still frequently lacking in that regard.³ Patients are becoming more informed and more providers are recognizing they need buy-in to treatment plans if those plans are to be successful. Shared decision-making is also being promoted through new policies in the United States and

elsewhere.⁴ If patients feel they have made a choice to adopt a treatment plan and that it fits with their goals, they may be more likely to adhere to it.⁵ More importantly, it is not within the rights of providers to make choices about potentially harmful interventions for an individual unless that person has been court-ordered to receive treatment, or in emergency situations when safety is threatened. For a person with dementia of a severity that he or she cannot make informed decisions about medical care, family members or other surrogate decision-makers can be engaged in many cases to make the choice they believe the patient would have made prior to losing decision-making capacity. When a patient or surrogate makes a decision, it is important that the decision be well-informed. This requires a thorough description of risks, benefits, and alternative treatments, presented in such a way that considers the decision maker's literacy level and other personal characteristics influencing their ability to make a truly informed decision.

An important contributor to people's ability to make informed choices is health literacy, "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions".⁶ The Institute of Medicine (IOM) reported that about 90 million U.S. adults, nearly half the adult population, have literacy skills that test below high school level.⁶ The 2003 National Assessment of Adult Literacy showed 88% of US adults lack proficient health literacy, impeding their ability to effectively manage their own or their loved ones' health.⁷

A systematic review examining the effects of health literacy on health outcomes and interventions to improve those outcomes found that low health literacy is associated with more hospitalizations; greater use of emergency care; lower receipt of mammography screening and influenza vaccine; poorer ability to demonstrate taking medications appropriately; poorer ability to interpret labels and health messages; and, among elderly persons, poorer health status and higher

mortality outcomes. Low health literacy may be a mediator of racial disparities in health outcomes.⁸ The IOM also found that hundreds of studies show health materials are written at a level exceeding the reading ability of the average US adult.⁶

The US Department of Health and Human Services National Action Plan to Improve Health Literacy has seven goals. On the information level, it supports developing and disseminating health and safety information that is accurate, accessible, and actionable. On the health system level, it encourages changes in the health care delivery system that improve health information, communication, informed-decision making, and access to health services. On the process level, it promotes increased development, implementation, and evaluation of practices and interventions to improve health literacy. Finally, it supports increased dissemination and use of evidence-based health literacy practices and interventions.⁹

To address health literacy-related challenges for families making decisions about using antipsychotic medications for patients with dementia, we sought to create an accurate, accessible, and actionable reader-friendly guide to help them participate in shared decision-making about whether using antipsychotic medication is right for their loved one. The guide is now available for broad dissemination. A team of clinicians and researchers with expertise in dementia created a draft handout with information and evidence they believed most important to discuss with a family member considering an antipsychotic medication for their loved one with dementia. Using plain language principles, a health literacy expert adapted and revised the handout into a reader-friendly decision-making guide. Direct feedback from people who would ultimately use written information is vital to improving its readability. Therefore, feedback was obtained through focus groups recruited from the New Readers of Iowa and the Alzheimer's Association, Greater Iowa Chapter. The New Readers are a group of adult learners who come together to learn from and support each other, and serve as spokespersons and advocates for adult literacy issues in their communities. The Alzheimer's Association provides vital services, education, and support to people living with the condition, as well as family members and caregivers affected by Alzheimer's. Details of these focus groups and feedback will be reported elsewhere.

Using the Fry formula,¹⁰ the final guide's reading level was calculated at 7.9. Its four numbered pages include the following reader-friendly features: question and answer

format to lead the reader through the document; simple pronunciation guides and a words-to-know section for complex words; clear information about risks and benefits, including what antipsychotic medications can and cannot help, side effects, starting with the most serious, and use of numbers rather than percentages; consistent headings, subheadings, and bullet lists; 13-point serif font; and a place to make notes and track side effects with a list of signs to monitor that suggest side effects. The concept of surrogate decision-making is also described in the context of the decision at hand. This reader-friendly guide promotes shared decision-making between providers and family members about antipsychotic use for patients with dementia, and may help curb inappropriate use of antipsychotic medication.

As efforts by the Centers for Medicare and Medicaid Services and others attempt to reduce antipsychotic use,¹¹ it is important to remember that patients and their families have much at stake. They should be involved in decisions about use of these drugs. Sometimes families are supportive of antipsychotic use because it might result in the best quality of life for their loved one, even though there are risks. In other cases they are appropriately skeptical of the need for an antipsychotic and may refuse, even if it sometimes means they will have to move their loved one to a different care setting if they do not agree to use an antipsychotic. As long as their decisions do not clearly compromise safety, these are their choices. The clinician's role is to provide advice and help guide them to the right decision, in addition to helping ensure safety.

You can find the shared decision-making guide and other free resources on behavior management in dementia [on the IA-ADAPT web site](#). Continuing education credit is available for completion of the training program. We would like to thank the New Readers of Iowa, the Greater Iowa Chapter of the Alzheimer's Association, and the rest of the Health Literacy Iowa and IA-ADAPT team members for their help in developing this resource, and thank the Agency for Healthcare Quality and Research for supporting the project.

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