Position Statement 35: Aging Well: Wellness and Psychosocial Treatment for the Emotional and Cognitive Challenges of Aging

Policy

Aging is a time of diminishing mental as well as physical capacities, and cognitive aging is best understood as simply another phase of life. Some people age more successfully than others, and many find new and deeper satisfaction in later life. But aging also brings with it the threat of serious mental health conditions, including dementia as well as depression, anxiety and sometimes psychosis, which will require greater attention as our society ages. Mental Health America (MHA) advocates studying and funding medical and psychosocial interventions to help sustain our mental health and quality of life as we age, and acting to maintain and recover wellness.

In coping with the mental health conditions associated with aging, as with any other serious mental health condition, "recovery" should be the goal. While a positive attitude can make an enormous difference in aging well, mental illnesses including dementia, which the Diagnostic and Statistical Manual of Mental Disorders -5[2] (DSM) refers to as "mild" and "major" "neurocognitive disorders," are not "normal" parts of aging, and should be identified and treated once it is clear that there is a probable disorder. This is as true with dementia as with any other mental health condition, though dementia has sometimes been thought of as different from other mental health conditions because it cannot be reversed.

Some confusion can be alleviated, some quality of living restored, by applying the lessons of "positive aging."[3] And people with all forms of dementia can benefit from psychosocial interventions, which Appendix A to this position statement examines in detail and contrasts with the relative lack of success in developing drugs to address dementia and related conditions. With better research and treatment, people can realistically hope to maintain better cognitive and emotional health in later life. MHA will refer to "positive aging" and "aging well" rather than "recovery" in the remainder of this position statement.

MHA urges that the budget discussions of all levels of government recognize the emerging needs of older people with mental health and substance use conditions, including cognitive health as a part of mental health. Innovative programs will be required to maintain and increase wellness as the American population goes through dramatic demographic change, and, "there is no health without mental health." This issue should emerge as a major focus of health care reform implementation under the Affordable Care Act, to contain costs and encourage wellness by promoting "aging well."

The overarching goals should be:

- to reduce isolation and enable older people with mental health or substance use problems to live where they prefer, generally in the community, as long as they can – to "age in place;"
- to assure access to clinically appropriate, culturally and linguistically competent care in the community and in congregate living settings for people who need more help as they grow older;

- to encourage people to age well by helping them to preserve their mental as well as general health and sense of vitality and fulfillment as they age;
- to prioritize public funding for psychosocial research and programs directed at aging well;
- to increase research into Alzheimer's disease and other forms of dementia and especially the anxiety, depression and psychosis that sometimes accompany cognitive impairment; and
- to use all available regulatory tools and "nudges" to encourage pharmaceutical industry, academic and public interest study of out-of-patent and "off-label" drugs that can alleviate suffering.

Background

The population of people over age 65 in the United States is projected to double between 2000 and 2030, from 35 million to 70 million.[4] While mental illness is not an inevitable part of aging, and older people actually experience fewer mental health conditions (excepting cognitive impairment) as they age, approximately 6.9% of people aged 65-74 experience "frequent mental distress,"[5] and many experience mental health and substance use conditions associated with loss of functional capacity even though a formal diagnosis may not be justified. Anxiety and depression and the psychotic symptoms of dementia in all its forms must be addressed for people to age well, and MHA envisions a supportive, integrated system of both psychosocial and medical care that encourages people to meet such challenges as they occur.

Older people with mental health problems are a diverse population including:

- people with lifelong serious and disabling mental illnesses;
- people with Alzheimer's disease and other forms of dementia (often with co-occurring episodic anxiety, depression, and psychosis);
- people with severe depression, anxiety, and emotional and behavioral problems that contribute to high rates of suicide, social isolation, and preventable institutionalization;
- people with less severe disorders that nevertheless limit their ability to age well; and
- people who abuse substances, primarily alcohol and pain medications, but increasingly including people with lifelong addictions and those who use illegal substances recreationally.

As stated by Deborah Padgett in the conclusion to her Handbook on Ethnicity, Aging, and Mental Health, aging need not be a time of "irreversible decline and loss," and depression and emotional distress can be mastered. She concludes: **"Declines usually associated with aging are quite malleable and influenced less by aging per se than by a host of psychosocial and lifestyle factors such as stress, diet, and exercise. Among the [most important] psychosocial factors associated with successful aging are sense of control and autonomy and social support."**[6] So "positive aging" can bring about overall wellness for individuals, focused on their personal goals and current place of residence, social support system, and community. The primary method is by strengths-based therapies[7] that build the healthy habits that MHA refers to as "wellness." These strengths and supports are critical to aging well.[8]

For the same reason, Padgett explodes the "double jeopardy" concept that has stigmatized "ethnic aging." After accounting for the underreporting common in minority communities, Padgett concludes that mental health conditions are no more prevalent in Black and Hispanic elders.[9] In

fact, she argues the contrary. Since, “adaptive [psychological, social and cultural strengths and] strategies formulated over a lifetime of struggle are keys to successful aging,”[10] elders of color who have coped with deprivation and stigma over their entire lives may have better mastered the skills required to cope with late life challenges.

Still, nearly half of people over age 65 with a recognized mental or substance use disorder have unmet needs for services.[11] Older adults with mental health or substance use conditions often do not seek specialty mental health care. They are more likely to visit their primary care provider– often with a physical complaint.[12] And though treatment can be an important component of aging well, misdiagnosis, especially by non-specialists, is a significant concern, as is overreliance on drugs rather than psycho-social treatment. The interaction among physical, emotional and behavioral conditions is complex in older people:

- Psychological stress may lead to general health problems;
- General health problems may lead to mental decompensation;
- Coexisting mental and general health challenges and responses may interact; and
- Social and psychosocial resources and medical and complementary treatments may affect all of the above.

Treatment works when older people are accurately diagnosed. But in older people, assessments of functional disabilities and prescriptions for concrete improvements in quality of life are more important than labels. By this definition, up to 80% of older people recover from depression with appropriate treatment.[13] But more research is needed on the unique mental health issues associated with Alzheimer’s disease and other forms of dementia to achieve equivalent results with cognitive impairment and its psychiatric symptoms.

The ramifications of lack of access, misdiagnosis, and poor treatment reach beyond the mental well-being of the individual. There are serious physical consequences of untreated mental illness. Older people with chronic medical conditions such as diabetes and heart disease and co-occurring depression are at increased risk for disability, premature mortality, and high health care costs. In addition, people with serious mental illness are at high risk for obesity, hypertension, diabetes, cardiac conditions, respiratory problems, and communicable diseases that contribute to a life expectancy many years less than that of the general population.

Older people also face inevitable life challenges with emotional consequences such as disability, retirement, loss of status, reduced physical and mental abilities, losses of family and friends, and the inevitability of death. Older people with mental health challenges face these challenges with diminished resources and have to work harder to age well.

Older people with mental health or substance use problems are not yet a public policy priority, and MHA is only beginning to tear down this silo by recognizing the extent to which cognitive health as an essential aspect of mental health. In addition, because their needs usually overlap the mental health, substance abuse, general health, and aging services systems, the mental health concerns of elders often fall between the cracks. Specialized mental health and substance use services have not secured the resources necessary to provide appropriate care and treatment for older people. The general shift in mental health policy towards evidence-based, individual-centered care, consumer empowerment and recovery has not been reflected in improved services for older people. The primary and institutional care services that are the main source of care and treatment for older people with mental illnesses and substance use disorders rarely identify the particular needs and interests of this group. There is a widespread failure to integrate the aging, mental health and substance use treatment systems. A literature

review shows the greatest support for **community-based, multidisciplinary, geriatric mental health treatment teams.**[14] But little of that is happening, yet.

Effective Services for Older People.[15]

Evidence-based health care should be the foundation for building exemplary care tailored to needs of our aging population. Evidence-based health care:

- supports flexible and individualized care based on individuals' unique needs, histories and other factors, and does not dictate "one-size-fits-all" treatment;
- develops research that is widely disseminated and vetted by advocates and people in treatment as well as researchers;
- develops research that appropriately represents all major cultural and linguistic groups so that group differences can be understood and addressed;
- focuses on prevention and treatment of Alzheimer's disease and other forms of dementia and of the entire range of related mental health symptoms;
- emphasizes safety and quality of life as the overarching goals; and
- supports informed decision-making and positive aging as the principal determinants of care.

A comprehensive service system should include:[16]

- outreach services, including community education and training, prevention and early intervention efforts, and screening and early identification;
- community-based, multidisciplinary, geriatric mental health treatment teams;
- comprehensive home and community based services, including integration with primary care, case management, peer and consumer-run services, caregiver supports, crisis services and long-term care;
- mental health promotion interventions that seek to improve the quality of life for older adults, not simply mitigate the negative effects of aging; and
- policy and legislative changes that address the problems of workforce development, funding, research, coalition-building and integrated service systems.

Integration of care is the key:

The vast majority of older adults with a mental health or substance use disorder also have other chronic conditions. Thus, it is critical to integrate mental health and substance use with other health services including primary care, specialty care, home health care, and residential-community-based care. There are various models for integrating mental health and general health services including:

- training primary care providers in mental health, co-locating health and mental health services, using integrated treatment teams of health and mental health professionals;
- using care managers to follow up with consumers outside of the office;
- establishing primary care centers that specialize in serving older adults with mental disabilities, establishing health satellites at mental health centers;
- using peers, or people with similar lived experience, to provide support to individuals with health and mental health problems; and
- using community-based, multidisciplinary, geriatric mental health treatment teams.

The “health home” and “accountable care organization” concepts embedded in the Affordable Care Act are the most recent federal initiatives promoting integration of care.[17] As of 2015, there were 744 ACOs, serving 7.8 million Medicare “lives.”[18]

The growth of ACOs slowed in 2014, and there are numerous barriers to sustaining these approaches, especially in the Medicare population, including:

- Providers lack knowledge of the various models for integrating mental health, substance use and general health services;
- Integration runs counter to the current service traditions. Providers tend to work independently rather than in collaboration;
- Older people’s mental health needs are not usually integrated into their overall discharge plan when they leave inpatient treatment;
- Cost can constrain options, as Medicare, Medicaid, and private insurance may not adequately reimburse for mental health and substance use services or collaborative care; and
- Research has not adequately addressed the psychosocial and pharmacological needs of older people, especially people with psychiatric symptoms that are associated with cognitive impairment.

Older people with mental health or substance use problems also often receive services and supports through social service agencies specializing in aging services. These include senior centers, case management, adult day care, and adult protective services. Unfortunately, there is currently a lack of cross-system knowledge and collaboration. Professionals who work in the specialty mental health, substance abuse, general health, or aging systems typically do not know about the services available in other systems, making it difficult to find appropriate services for older people.

Workforce Development.

The behavioral healthcare system is not ready for the elder boom, which is predicted to hit in full force as the baby boomers retire. The diminishing workforce trained in geriatric mental health issues is of particular concern. Although peer support has shown its worth with younger adults, it has yet to be widely adapted to older people in need of assistance and support. Research supporting the use of peer support with this population is needed, along with training and implementation of this new workforce. It is also imperative that training in geriatric mental health be expanded and incorporated into curricula for health care professional education, especially for physicians, nurses, psychiatrists, psychologists, social workers, mental health counselors, peer specialists, and rehabilitation specialists. Currently there are roughly 2,425 geriatric psychiatrists in the United States with an estimated current need for 4,400 and a future need for 8,840. In regards to geriatric social workers, there are only 6,000 nationwide with a current need for 32,600 and a future need for 65,480.[19]

The Dementia Dilemma.

In addition to mental health conditions, older people suffer from Alzheimer’s disease and from the eight other “neurocognitive disorders” identified in the DSM according to their “medical causes,” though the more recent literature has cast some doubt on those distinctions. Older people also experience what the DSM calls “mild neurocognitive disorders,” lesser declines in mental acuity often referred to as “mild cognitive impairment,” which may range from absent-

mindedness to serious loss of mental functioning. An excellent 2015 summary, written in plain language by Berkeley Wellness, a publication of the University of California, can be found at http://www.berkeleywellness.com/healthy-mind/memory/article/could-we-stop-alzheimers?s=EFA_151003_AA1&st=email&ap=ed

The defining characteristic of dementia is significant impairment in activities of daily living. Most often, the clinical formulation of dementia is linked primarily to cognition, although such intellectual changes are often associated with behavioral changes, ranging from irritability and agitation to psychosis with hallucinations and delusions. Early onset Alzheimer's disease is more easily defined as a distinct disease, but late onset dementia is often a mixed pathology. Plaques and tangles are not unique to Alzheimer's disease. The overlapping and labile symptoms and physiological markers of dementia are such that controversy continues over the capacity to distinguish Alzheimer's disease, even with a PET scan or in an autopsy, from the other forms of dementia identified in the DSM: Huntington's disease (a genetic disorder that is better identified through genetic testing), Parkinson's disease, Lewy body disease,[20] frontotemporal degeneration, traumatic brain injury (identified from the injury rather than a brain scan), prion ("mad cow") disease, HIV infection (identified by viral load tests), and vascular disease (atherosclerosis or "hardening of the arteries). Our diagnostic categories will surely evolve as we learn more.

This means that as people age, wellness matters more, not less, making activities like exercise, a good diet, reading, art, music, social interaction, study and service increasingly important even as the inertia of our aging bodies heads for the couch and the television set. Anyone who lives long enough will experience the struggles of cognitive aging, whether or not diagnosed with the dementia label. But the loss need not swallow up the person, no matter what the label, and effort can produce results.

Despite the fervent hope of Alzheimer's advocates, there is no pill on the horizon that is likely to cure Alzheimer's disease or any other form of dementia. At best, symptoms may be delayed and complications averted. Nor is Ginkgo biloba21 or any other substance going to prevent the aging of the brain, though some people may be helped by a variety of interventions that should be more studied and better understood. But cognitive impairment can in fact be slowed by a supportive system of psychosocial care grounded in the logic of positive aging. The emerging issues in the treatment of dementia are addressed in Appendix A to this position statement.

In Preventing Cognitive Decline and Dementia:

A Way Forward, the National Academies Press published the conclusions of a 2017 review of the available evidence documenting interventions to prevent cognitive decline and dementia.

This followed up on the National Academies' 2010 finding that there was insufficient evidence at that time to make recommendations about interventions to prevent cognitive decline and dementia. Since then, understanding of the pathological processes that result in dementia has significantly advanced, and a number of clinical trials of potential preventive interventions have been completed and published. Listed contributors to the report included Alan I. Leshner, Story Landis, Clare Stroud, and Autumn Downey, Editors; Committee on Preventing Dementia and Cognitive Impairment; and Board on Health Sciences Policy; Health and Medicine Division; National Academies of Sciences, Engineering, and Medicine.

According to the report, 2017 AHRQ review endorsed by the National Academies, conducted by the Minnesota Evidence-based Practice Center (EPC), "represents an extensive effort to

summarize the state of the evidence in this area. It examines the evidence on the effectiveness, comparative effectiveness, and harms of interventions associated with preventing or delaying the onset or slowing the progression of CATD and MCI and delaying or slowing ARCD. The systematic review relies primarily on randomized controlled trials (RCTs) with a minimum 6-month follow-up period for intermediate outcomes; large prospective quasi-experimental cohort studies with comparator arms (n >250 per arm) were also included in the search conducted for the review, but little concrete evidence emerged from such studies.

Overall, the committee determined that, despite advances in understanding these conditions since the 2010 AHRQ systematic review was conducted, the available evidence on interventions derived from RCTs—the "gold standard" of evidence—remains relatively limited and has significant shortcomings. These shortcomings stem, in part, from the challenges inherent in conducting RCTs on interventions for conditions that may have a long latency period and are often comorbid with other late-life conditions. As described in more detail below, methodological shortcomings also contributed to the paucity of high-quality RCT data available to support recommendations on public health messaging.

To supplement this evidence base, therefore, the committee considered additional evidence from observational nonexperimental studies—primarily longitudinal population-based cohort studies—as well as evidence from studies of risk factors and neurobiological studies that strengthen belief in the effectiveness of a class of interventions for which at least some supportive RCT data were identified. Although observational data are subject to their own limitations (e.g., risk of confounding, biases) and should be interpreted with caution, such studies are, if conducted using rigorous methods, an important complementary source of evidence when definitive RCT data are lacking. Knowledge of harms and costs, as well as potential benefits to noncognitive outcomes, was also considered. The AHRQ systematic review identified no specific interventions that are supported by sufficient evidence to justify mounting an assertive public health campaign to encourage people to adopt them for the purpose of preventing cognitive decline and dementia. The systematic review did, however, find some degree of support for the benefit of three classes of intervention: cognitive training, blood pressure management in people with hypertension, and increased physical activity."

A Better Future

This analysis brings us full circle. Although some hope is held out for new drug or genetic therapies, Appendix A shows that psychosocial and public health measures are more effective in treating dementia. As Peter Whitehouse concluded in a recent essay:

Psychosocial interventions such as caregiver education, support groups, arts interventions, and other community programs have been demonstrated to improve quality of life. No drugs have been demonstrated to do the same (George and Whitehouse, 2010, Whitehouse and George, 2014, Portacone, Berridge, Johns, and Schicktanz, 2013, D'Alton, Hunter, Whitehouse, Brayne, and George, 2014, Katz and Meller, 2013).[22]

Having a sense of purpose and a community network in which to manifest that purpose seems to be important for brain health, an important component of aging well. But positive aging starts with more basic work --

- Stay Positive.
- Get Physically Active.

- Get Enough Sleep.
- Eat Well.
- Connect with Other People.
- And Take Care of Your Spirit.

Call To Action

- Aging well is everyone's business. A positive aging agenda will require dramatic expansion of available services—including:access to appropriate housing and social supports;
    - a focus on quality of life and person-centered goals;
    - integration of care among the mental health, health, substance use, and aging services systems;
    - building a much larger clinically and culturally/linguistically competent workforce; and
    - increasing and re-inventing funding sources to develop a match between funding mechanisms and service needs.
- Health care reform is a promising avenue for promoting positive aging. Aging well and specialized behavioral, cognitive and emotional health needs should be priorities in the care of older people under the Affordable Care Act and in any changes made to Medicare.
- Affiliates are urged to adopt an aging well agenda for their communities, and promote it in partnership with others, since many services, especially housing, will need to be provided by local and state governments and nonprofit agencies.
- Affiliates may act as catalysts to make elder cooperative and congregate care more available in their communities.
- Research is urgently needed to understand the causes of Alzheimer's disease and other dementias and how to prevent and treat both the dementia itself and the depression, psychosis and anxiety that often accompanies it. Affiliates should encourage the development of community-based psychosocial programs to meet these emerging needs.
- The federal, state and local governments and non-profit agencies and foundations should fund demonstration projects to explore new psychosocial treatments for dementia and co-occurring conditions and to improve the evidence base for those that exist. Psychosocial treatments have been shown to be more effective than drug therapies and should be promoted and used more extensively in the absence of approved drug therapies and in recognition of the substantial adverse side effects of the off-label drug therapies now being used.
- MHA urges much more research and public education concerning cholinesterase inhibiters, glutamate antagonists, antidepressants, antipsychotics and anxiolytics for use in dealing with dementia and its symptoms and co-occurring conditions. See Appendix A for more details.
- If additional authority is needed for the FDA to insist on full disclosure and additional studies of drugs being marketed and used off-label as frequently as are antipsychotics and benzodiazepines, MHA strongly supports congressional action to grant such authority. In addition, the FDA should use the full range of enforcement incentives and "nudges" that it can devise to get these drugs properly evaluated and controlled. Academic researchers and public interest organizations like the Cochrane Collaboration should be recruited to help.

- MHA urges the pharmaceutical industry to help build and publicize an evidence base to help people with dementia who lack access to on-label medications to treat psychotic symptoms and anxiety.

APPENDIX A

Treatment of Cognitive Aging and Dementia

Promoting Wellness

Validation Therapy

Nursing Protocols

Other Psychosocial Initiatives

Drug Therapies for Dementia (Cholinesterase Inhibitors)

Drug Therapies for Depression, Anxiety and Psychosis Related to Dementia

Antipsychotics

Emphasize Non-drug Interventions to treat Psychosis

Comparative Effectiveness and Comparative Side Effect Prevalence Analysis Required

Anxiolytics

In a 2015 study of “Cognitive Aging,” the IOM counseled that “cognitive aging is a natural process that can have both positive and negative effects on cognitive function in older adults—effects that vary widely among individuals.” It identifies and promotes actions that individuals, organizations, communities, and society can take to help older adults maintain and improve their cognitive health. The IOM assesses the state of knowledge about cognitive aging, including definitions and terminology, epidemiology and surveillance, prevention and intervention, education of health professionals, and public awareness and education. It is a good place to start in understanding what we now know about the aging brain.[23]

Similarly, researcher/clinicians like the once-controversial Peter Whitehouse have begun treating dementia and cognitive impairment on a continuum, and used a positive aging model as a way to respond. [24] Quality of life and the interventions to preserve and restore it differ by individual more than by diagnosis. The most demonstrated improvement is with psychosocial, rehabilitative approaches. In this view, “dysfunction and disability are more important than precise diagnosis; quality of life trumps cognitive enhancement; community engagement is key; and population health perspectives gain influence over individual health.”[25]

With brains, as with so much else in life, “you use it or you lose it.” Those most involved in life are the most likely to stay involved and stay well. “Neurodegenerative conditions do not ‘claim’ older people, nor do they dominate them or degrade their humanity. They simply alter how they live their lives.”[26] Effective prevention and appropriate treatment of all kinds of dementia may be the greatest public health challenge posed by the aging of the boomers.

Promoting Wellness

As with any mental health condition, both cognitive aging and dementia are best addressed early and often. The IOM recommends that individuals should:

- Be physically active.
- Reduce and manage cardiovascular disease risk factors (including hypertension, diabetes, and smoking).
- Regularly discuss and review health conditions and medications that might influence cognitive health with a health care professional…. A number of medications can have a negative effect on cognitive function when used alone or in combination with other medications. The effects can be temporary or long-term.
- Take additional actions that may promote cognitive health, including [remaining] socially and intellectually engaged, and engage[ing] in lifelong learning.
- Get adequate sleep and receive treatment for sleep disorders if needed. [and]
- Be aware of the potential for financial fraud and abuse, impaired driving skills, and poor consumer decision making, and make health, finance, and consumer decisions based on reliable evidence from trusted sources.

In 2009, MHA launched a website (no longer active) called "Live Your Life Well," intended to promote mental wellness through ten straightforward steps:

- Connect with Others. People who feel connected are happier and healthier--and may even live longer.
- Stay Positive. People who regularly focus on the positive in their lives are less upset by painful memories.
- Get Physically Active. Exercise can help relieve insomnia and reduce depression, and reduce chronic disease.
- Help Others. People who consistently help others experience less depression, greater calm and fewer pains.
- Get Enough Sleep. Not getting enough rest increases risks of weight gain, accidents, reduced memory and heart problems.
- Create Joy and Satisfaction. Positive emotions can boost your ability to bounce back from stress.
- Eat Well. Eating healthy food and regular meals can increase your energy, lower the risk of developing certain diseases and influence your mood.
- Take Care of Your Spirit. People who have strong spiritual lives may be healthier and live longer. Spirituality seems to cut the stress that can contribute to disease. Spirituality does not necessarily involve religion. Art and music are forms of spirituality.
- Deal Better with Hard Times. People who can tackle problems or get support in a tough situation tend to feel less depressed. [and]
- Get Professional Help if You Need It. More than 80 percent of people who are treated for depression improve.

Validation Therapy

"Validation therapy" is a prototype of the psychosocial approaches now being developed for older people with cognitive impairments and dementia. Social worker Naomi Feil has written extensively and maintains a consultancy[27] promoting validation therapy. The basic principle of

the therapy is the reciprocated communication of respect, which communicates that the other's opinions and feelings are heard, understood, acknowledged, and (regardless whether or not the listener actually agrees with the content) that the person is being treated with genuine respect, rather than being marginalized or dismissed.

Validation therapy uses specific techniques, and it has attracted criticism from researchers who dispute the evidence, which is generalized rather than specific, and thus difficult to synthesize in a meta-analysis. There is not yet enough rigorous evidence proving the efficacy of validation therapy, but it is a promising practice, harmless and an important line of defense as caregivers confront the anxiety, depression and psychosis that often come with cognitive impairment.

Nursing Protocols

Nursing protocols appropriately emphasize psychosocial interventions. Thus, the AHRQ National Guideline Clearinghouse[28] recommends:

The Progressively Lowered Stress Threshold (PLST) provides a framework for the nursing care of individuals with dementia.

- Monitor the effectiveness and potential side effects of medications given to improve cognitive function or delay cognitive decline.
- Provide appropriate cognitive-enhancement techniques and social engagement.
- Ensure adequate rest, sleep, fluid, nutrition, elimination, pain control, and comfort measures.
- Avoid the use of physical and pharmacologic restraints.
- Maximize functional capacity: maintain mobility and encourage independence as long as possible; provide graded assistance as needed with ADLs and IADLs; provide scheduled toileting and prompted voiding to reduce urinary incontinence; encourage an exercise routine that expends energy and promotes fatigue at bedtime; and establish bedtime routine and rituals.
- Address behavioral issues: identify environmental triggers, medical conditions, caregiver–patient conflict that may be causing the behavior; define the target symptom (i.e., agitation, aggression, wandering) and pharmacological (psychotropics) and nonpharmacological (manage affect, limit stimuli, respect space, distract, redirect) approaches; provide reassurance; and refer to appropriate mental health care professionals as indicated.
- Ensure a therapeutic and safe environment: provide an environment that is modestly stimulating, avoiding overstimulation that can cause agitation and increase confusion and under-stimulation that can cause sensory deprivation and withdrawal. Utilize patient identifiers (name tags), medic alert systems and bracelets, locks, and wander guard. Eliminate any environmental hazards and modify the environment to enhance safety. Provide environmental cues or sensory aids that facilitate cognition, and maintain consistency in caregivers and approaches.
- Encourage and support advance-care planning: explain trajectory of progressive dementia, treatment options, and advance directives.
- Provide appropriate end-of-life care in terminal phase: provide comfort measures including adequate pain management; weigh the benefits/risks of the use of aggressive treatment (e.g., tube feeding, antibiotic therapy).
- Provide caregiver education and support: respect family systems/dynamics and avoid making judgments; encourage open dialogue, emphasize the patient's residual

strengths; provide access to experienced professionals; and teach caregivers the skills of caregiving.
- Integrate community resources into the plan of care to meet the needs for patient and caregiver information; identify and facilitate both formal (e.g., Alzheimer's associations, respite care, specialized long-term care) and informal (e.g., churches, neighbors, extended family/friends) support systems.

Other Psychosocial Initiatives

Many exercise, educational, hobby, craft and other initiatives have been developed to promote positive aging, and senior centers and congregate care facilities all provide some level of stimulation and wellness education. A particularly interesting model is the Intergenerational School, a three-campus charter school in Cleveland, Ohio that uses elders as an integral part of its staff and curriculum. The Intergenerational School has been nationally recognized for its innovative, intergenerational approach to learning.[29]

Brain games are a more recent innovation, using computer software to stimulate cognition. But a 2014 Stanford consensus report[30] largely debunked the currently-available products:

- Many claims are “exaggerated and misleading” and exploit the anxiety of healthy older adults worried about memory loss. There’s no convincing evidence that any brain training programs will improve general cognitive abilities or help prevent or treat dementia.
- The companies often boast that their programs are designed by famous scientists and supported by solid research, but most of the studies they cite are small, short, and poorly designed, and many are conducted by researchers with financial interests in the products. The findings are often only tangentially related to the advertised claims. What’s more, it’s unclear whether any improvements in skills practiced in brain games would persist until even the next day or carry over to other cognitive tasks and daily living.
- The best brain-health advice, based largely on observational findings, is to lead a physically active, intellectually challenging, and socially engaged life, the authors wisely concluded. In particular, much research shows that physical exercise is a moderately effective way to maintain and even improve brain fitness. As the report pointed out, “If an hour spent doing solo software drills is an hour not spent hiking, learning Italian, making a new recipe, or playing with your grandchildren, it may not be worth it.”

Research is desperately needed to guide essential psychosocial treatment, but more importantly, MHA calls for innovation, including increased use of peer counseling to increase stimulation and decrease anxiety, technological applications to supplement a failing memory, interactive, voice-activated programs to minimize data entry issues, sophisticated monitoring and GPS location programs to keep people oriented in space and time, and various kinds of household robots to allow people to live in their own hopes with minimal help. Over time, and with a focus on peer support, whole communities can be redesigned to promote aging well.

Drug Therapies for Dementia (Cholinesterase Inhibitors)

Unfortunately, current drug therapies for Alzheimer’s disease and other dementias are not very effective and, despite FDA approval, are controversial for that reason. Drug therapies to deal with the anxiety and psychosis that often accompany the cognitive symptoms of dementia are off-label, little studied, and thus even more controversial. Dementia treatment is not an issue

that MHA has addressed in the past, but the serious deficiencies of existing prescribing practices demands scrutiny. The next sections of this position statement will provide guidance for the present and advocacy for the future, with the caveat that psychosocial interventions should both precede and accompany drug therapy, and that while no cure is in sight, MHA holds out hope that some of the many current research initiatives will prove fruitful.

There is no magic pill to prevent the aging of the brain or the other causes of dementia. But the U.S. Food and Drug Administration (FDA) has approved three cholinesterase inhibitors -- donepezil (Aricept), rivastigmine (Exelon) and galantamine (Razadyne) -- and one glutamate antagonist -- memantine (Namenda) — to treat the cognitive symptoms (memory loss, confusion, and problems with thinking and reasoning) of Alzheimer's disease.[31] Doctors sometimes prescribe both types of medications together. Some doctors also prescribe high doses of vitamin E for Alzheimer's disease, although that that is becoming less common.[32]

Although current medications cannot cure Alzheimer's or stop it from progressing, they may help lessen symptoms, such as memory loss and confusion, but only for a limited time. As stated by Consumer Reports:[33]

"…[A]fter six months on the drugs, most of the patients show no improvement in mental functioning, based on their doctors' assessments and tests of basic thinking skills. **Among the few who do benefit, the improvement is typically slight.** The available studies have not shown that the drugs help achieve what we would consider major goals of dementia treatment, prolonging people's ability to live independently or improving quality of life for either patients or caregivers," [Consumer Reports reported].

Even a small benefit or chance of improvement might be worth it if Alzheimer's drugs were risk free. But they are not. They can cause side effects such as insomnia, nausea, muscle cramps, diarrhea, and reduced appetite, all of which can be troublesome for people with dementia. Rarely, the drugs may cause more serious side effects such as internal bleeding and a slowed heart rate that could be potentially dangerous."

Cholinesterase inhibiters are widely endorsed and used. However, they are expensive, and the effect is modest at best. There is some evidence of permanent worsening of symptoms upon discontinuation of treatment,[34] so once started, it may be hard to stop until late in the course of the disease. But there are inadequate data to substantiate this concern. The Cochrane Dementia and Cognitive Improvement Group's[35] 2006 review concluded:

The results of ten randomized, double blind, placebo controlled trials demonstrate that treatment for six months, with donepezil, galantamine or rivastigmine at the recommended dose for people with mild, moderate or severe dementia due to Alzheimer's disease produced improvements in cognitive function, on average -2.7 points (95%CI -3.0 to -2.3, $p<0.00001$), in the midrange of the 70 point ADAS-Cog Scale. Study clinicians rated global clinical state more positively in treated patients. Benefits of treatment were also seen on measures of activities of daily living and behavior. **None of these treatment effects are large.**

The effects are similar for patients with severe dementia, although there is very little evidence, from only two trials.

A 2012 Cochrane review focused on Parkinson's disease and dementia with Lewy bodies was more positive:

The clinical features of dementia with Lewy bodies (DLB) and Parkinson's disease with dementia (PDD) have much in common. As patients with DLB and PDD have particularly severe deficits in cortical levels of the neurotransmitter acetylcholine, blocking its breakdown using a group of chemicals known as cholinesterase inhibitors may lead to clinical improvement. **Six trials showed a statistically significant improvement in global assessment, cognitive function, behavioral disturbance and activities of daily living rating scales in PDD and cognitive impairment in Parkinson's disease (CIND-PD) patients treated with cholinesterase inhibitors.**

However, the effect is still modest. Finally, the conclusions of a 2012 Cochrane review of studies of the use of cholinesterase for mild cognitive impairment were quite negative:

There is very little evidence that cholinesterase inhibitors affect progression to dementia or cognitive test scores in mild cognitive impairment. This weak evidence is overwhelmed by the increased risk of adverse events, particularly gastrointestinal. Cholinesterase inhibitors should not be recommended for mild cognitive impairment.

Until a political decision was made to make cholinesterase inhibiters generally available in the U.K., the U.K. National Health Service attempted to restrict reimbursement,[36] and experts like Peter Whitehouse[37] continue the dialogue in the United States. However, on balance, Whitehouse agrees that, in the current state of knowledge, he would be willing to prescribe cholinesterase inhibitors for dementia, because the effect, though small and by no means assured, could still be significant for the individual. **People in treatment need to understand this background to be able to decide whether or not to start on dementia drugs in light of the evidence, which is positive only for Parkinson’s and Lewy body dementia, demonstrates only modest relief of symptoms at best, does not demonstrate any slowing of the disease process, discourages use in mild cognitive impairment, and indicates a risk both in using and in discontinuing the medication.**

The truth is that we still know very little about the pathology of dementia, and the increasing focus on Alzheimer’s disease, while helpful in focusing attention on the riddle of dementia, obscures the individual factors that make each diagnosis unique:

Perhaps everyone’s Alzheimer’s condition or dementia is unique to them because different individual processes are involved throughout the life-course, including factors like head injuries, diet, alcohol consumption, and a panoply of social determinants of health, including air and water quality. Moreover, in the last several decades increasing overlaps between aging and dementia and among types of dementias have become more apparent. Neuronal loss, plaques, and tangles all can occur in individuals who do not have a clinically apparent dementia. Moreover, these features can occur in other conditions such as Parkinson’s and frontal lobe dementia. Our ability to differentiate these overlapping conditions from each other, much less from processes associated with aging, remain rudimentary. Even the allegedly clear-cut distinction between vascular disease and neurodegenerative disease is getting muddier the more we look at risk factors and biological markers.[38]

This aptly describes a scientific tangle every bit as complicated as the tangles associated with dementia. More research is clearly necessary and may someday help American society to cope with what is likely to become an epidemic as our population ages. The key is to pursue research into psychosocial as well as pharmacological interventions.[39]

Drug Therapies for Depression, Anxiety and Psychosis Related to Dementia

Causes of and treatments for Alzheimer's disease and other forms of dementia are riddles that future research must address. But there are critical, practical issues that must be addressed right now in managing the psychiatric symptoms of cognitive impairment, and it is an indictment of our drug regulatory system that they are only now being addressed at all.

People with dementia experience anguish and anxiety from life crises and loss of mental capacities and often have psychotic and depressive symptoms as well, and the agitation, depression and psychotic features impair quality of life, perhaps even more than the cognitive symptoms in many people. For example, many people with dementia do not recognize where they are, even in their own home, or who is taking care of them, and feel unsafe, anxious and depressed. In the absence of data specific to older people or people with dementia, these symptoms have been treated with medications approved for anxiety (principally benzodiazepines), depression, and psychosis. Antidepressants are effective in treating co-occurring depression and have not yet been controversial,[40] though testing in elderly populations has lagged. The widespread off-label use of antipsychotics has raised the greatest problems. However, the use of benzodiazepines for anxiety is being called into question as well. They are effective but potentially addictive and definitely exacerbate delusions. Thus, their use should at least be minimized.

Antipsychotics

In the absence of U.S. Food and Drug Administration (FDA) guidance, physicians have used off-label antipsychotics to treat psychotic symptoms of dementia. As of 2010, one-quarter of nursing-home residents had used antipsychotics.[41] The U.S. General Accounting Office (GAO) found that by 2012, the proportion had risen to one third.[42] MHA agrees with the GAO that these percentages are an indictment of the long-term care industry.

The available scientific evidence is weak, as pointed out in a 2005 JAMA review:

- For typical antipsychotics,…[g]enerally, no difference among specific agents was found, efficacy was small at best, and adverse effects were common. Six RCTs [randomized controlled trials] with atypical antipsychotics were included; results showed modest, statistically significant efficacy of olanzapine and risperidone, with minimal adverse effects at lower doses. Atypical antipsychotics are associated with an increased risk of stroke. There have been no RCTs designed to directly compare the efficacy of typical and atypical antipsychotics. Five trials of antidepressants were included; results showed no efficacy for treating neuropsychiatric symptoms other than depression, with the exception of one study of citalopram. For mood stabilizers, three RCTs investigating valproate showed no efficacy. Two small RCTs of carbamazepine had conflicting results. Two meta-analyses and six RCTs of cholinesterase inhibitors generally showed small, although statistically significant, efficacy. Two RCTs of memantine also had conflicting results for treatment of neuropsychiatric symptoms.

Pharmacological therapies are not particularly effective for management of neuropsychiatric symptoms of dementia.[43]

NAMI summarized the evidence on Treatment of Behavioral and Psychological Symptoms of Dementia in 2014 as follows:

- Atypical antipsychotics (6 RCTs) – Modest but statistically significant effects – Few adverse events at lower doses BUT: ~1.6-1.7 fold increase in mortality in active treatment over placebo – Rate of death in drug-treated patients was about 4.5%, compared to a rate of about 2.6% in the placebo group. Deaths due to heart related events (e.g., heart failure, sudden death) or infections (mostly pneumonia), cerebrovascular adverse events, hyperglycemia and diabetes mellitus.
- Typical antipsychotics (2 RCTs) – Minimal efficacy, frequent adverse events (may be severe) – [Associated with significantly higher adjusted risk of death relative to atypical antipsychotics -- MHA contests this assertion. Both typical and atypical antipsychotics are associated with significantly higher adjusted risk of death.[44]]
- Mood stabilizers/antidepressants (5 RCTs) – No efficacy on neuropsychiatric symptoms except depression.
- Antiepileptic drugs (5 RCTs) – No efficacy with valproate; conflicting results with carbamazepine.
- Cholinesterase Inhibitors (6 RCTs) – Minimal effect/conflicting results; statistically significant in 2 RCTs.
- Memantine (2 RCTs) – Conflicting results.[45]

Few studies of these drugs have been done in older people and in dementia of various types. Antipsychotics are widely used even though they increase the risk of death in elders. As has been documented in a recent (2015) serialized book by Steven Brill, published by the Huffington Post,[46] drug companies have promoted off-label use of antipsychotics without seeking FDA approval for their claims.

This situation requires a little explanation. The FDA reviews drugs for efficacy and safety and approves drugs for specific conditions. These are the labeled indications. The FDA does not regulate or monitor physicians, who are governed only by state licensure and civil malpractice. Clinicians with appropriate state licensure may prescribe any drug approved by the FDA for any purpose for any other condition that they believe warrants using the drug, without regard to the FDA label. This is called “off-label use.” In recent years, drug companies have been more assertive in marketing drugs. They have sometimes promoted off-label use, as illustrated by the following cautionary tale:

Despite the lack of FDA approval of its “second generation” “atypical” antipsychotic Risperdal (risperidone) for use in older people or in people with dementia, and a 2005 express FDA “black box” WARNING -- **Warning: Increased mortality in elderly patients with dementia-related psychosis** – the manufacturer thereafter aggressively marketed risperidone “for simple symptoms of dementia or restlessness.”[47] In a plea agreement resolving these charges, it conceded that it illegally promoted Risperdal to health care providers “for treatment of psychotic symptoms and associated behavioral disturbances exhibited by elderly, non-schizophrenic dementia patients.”[48]

The dilemma for a family or a person in treatment is that there is no pharmaceutical treatment approved by the FDA for treatment of psychotic symptoms and associated behavioral disturbances exhibited by elderly people with dementia who do not have schizophrenia, even though the DSM 5 expressly states that antipsychotics are used for that purpose. Thus, if available psychosocial care is inadequate to deal with the symptoms, when the family or the care facility has run out of options, a typical or atypical antipsychotic will be prescribed off-label. Based on an unscientific sample collected by MHA, hospice programs often prescribe haloperidol (Haldol), an older and cheaper typical antipsychotic, while psychiatrists generally use atypical antipsychotics. But all use extremely low doses, and clinicians and care workers

alike claim that the drugs are effective in a significant number of patients, based on their experience.

Yes, the evidence is weak, and there is a significant risk of stroke and other side effects, but if available psychosocial approaches fail, antipsychotic drugs will be used to deal with psychotic symptoms, especially when needed to preserve the safety of the staff and other people in treatment, and to avoid the use of seclusion and restraints. Why then is someone not busy studying risperidone and other anti-psychotics and working on comparisons and improvements right now?

The general answer is that private funding now dictates the direction of most research. “When looking at the numbers, I see an imbalance,” said Stephan Ehrhardt, an associate professor in the Johns Hopkins Bloomberg School of Public Health’s Department of Epidemiology, in a 2015 study. “Industry doesn’t fund trials most important for public health because they have no incentive to do that.”[49]

This trend has emerged as the budget for the National Institutes of Health— the primary source of government funding for clinical trials — has been slashed 24 percent since 2006 amid belt-tightening in Washington. The drug and medical device industry now funds six times more clinical trials than the federal government, according to the Johns Hopkins University researchers. That means companies with financial interests in the studies now have more control over what doctors and patients learn about new treatments. And pharmaceutical companies are unlikely to address the use of antipsychotics in dementia care:

First, because most antipsychotics are now out-of-patent, and there is little profit to be made.

Second, because there are significant ethical issues whenever people have complicated medical conditions, as the elderly always do, and whenever competency is in question, as it is in anyone with dementia.

And third, because the risk/benefit equation is skewed, and the public policy that favors finding a reliable drug and demonstrating its reliability to treat the psychiatric symptoms of dementia has been ignored in prioritizing punishing manufacturers for promoting off-label uses.

MHA believes that a more significant additional sanction would be to require the manufacturer to conduct and disclose studies to back up its claim. If additional authority is needed for the FDA to insist on full disclosure and additional studies of drugs being marketed and used off-label as frequently as are antipsychotics, MHA strongly supports congressional action to grant such authority. In addition, the FDA should use the full range of enforcement incentives and “nudges” that it can devise to get these drugs properly evaluated and controlled. Academic researchers and public interest organizations like the Cochrane Collaboration should be recruited to help. And NIH funding should be increased to focus more research on these drugs and others with major public health implications.

Finally, MHA urges the pharmaceutical industry, in the public interest, to help build an evidence base of published and unpublished studies that it has conducted of the use of anti-psychotics to treat psychiatric conditions associated with dementia. Whenever possible, the federal government should insist, in the interest of science, that ALL such studies be made available to the public.

Psychotic symptoms of dementia are difficult for patients, clinicians, families and caregivers to deal with. Fortunately, the American Psychiatric Association has published a Practice Guideline (issued in May, 2016) that can help guide clinicians, families and people in treatment until better evidence is available. The Practice Guideline, published by the APA in 2016,[50] provides:

- Non-emergency antipsychotic medication should only be used in patients with dementia when agitation and psychosis symptoms are severe, are dangerous and/or cause significant distress to the patient.
- Response to non-drug interventions should be reviewed prior to use of antipsychotic medication.
- Before treatment with an antipsychotic, the potential risks and benefits should be assessed by the physician and discussed with the patient and the patient's surrogate decision maker, with input from the family.
- Treatment should be initiated at a low dose and eased up to the minimum effective dose.
- If the patient experiences significant side effects, the risks and benefits should be reviewed to determine if the antipsychotic should be discontinued.
- If there is no significant response after a 4-week time period, the medication should be tapered and withdrawn.
- In patients who show adequate response to the medication, an attempt to taper and withdraw the antipsychotic should be made within four months of starting.
- In patients whose antipsychotic medications are being tapered, symptoms should be assessed at least every month during tapering and for at least four months after the medication is discontinued.
- A long-acting injectable antipsychotic should not be used unless it is administered for a co-occurring chronic psychotic disorder.
- If non-emergency antipsychotic medication treatment is to be used, haloperidol should not be used first.

While the focus of the guidelines is antipsychotic therapy, they emphasize that any such medication given to dementia patients should be just one part of a comprehensive treatment plan that is person-centered and includes appropriate drug and non-drug treatments.

Medication needs more study, but it must be stressed: It is not the only answer. We need good research on psychosocial treatments as well.

Comparative Effectiveness and Comparative Side Effect Prevalence Analysis Required

Haloperidol (Haldol) is an older antipsychotic used frequently to treat the psychotic features of dementia, especially as part of a program of palliative care, but there are no studies validating its use for that off-label purpose. It went out of patent in 1986. Risperidone (Risperdal and generics), Seroquel (quetiapine) and Zyprexa (olanzapine) are the “atypical” antipsychotics currently being used off-label for psychotic symptoms of dementia, which are thought by psychiatrists to be preferable because the side effects (especially tardive dyskinesia) are less frequent than with haloperidol. However, the listed side effects are substantial in the more recent drugs as well, and there are no data on the relative prevalence of side-effects. The FDA refused to allow any comparative effectiveness or comparative side effect language on the risperidone label. Risperidone is now out-of-patent as well. All antipsychotics have serious side effects.

Major government and professional society efforts have emerged to try to decrease the use of antipsychotic drugs, particularly in long-term care.[51] For all antipsychotics, the FDA requires a warning that the drug is not approved for treatment of dementia-related psychosis and may increase the risk of death. Quetiapine has the anti-depressant black box warning concerning the increased risk of suicide as well. Obviously, these warnings have had little if any effect in discouraging off-label use.

Other antipsychotics that may be used to treat psychotic features of dementia include asenapine (Saphris), iloperidone (Fanapt), paliperidone (Invega or Sustenna), and ziprasidone (Geodon). These have side effects and warnings similar to those of the three drugs discussed above. MHA advocates that all of these drugs be carefully tested through a comparative effectiveness and safety analysis for use to alleviate psychotic features of dementia and that the labels be amended to give more guidance as soon as possible.

Emphasize Non-drug Interventions to treat Psychosis

Although there are times when drug treatment is the only alternative, psychosocial techniques should be tried first, and may be more effective, according to 2015 British Medical Journal study.[52] Dr. Helen Kales, a psychiatrist who directs the University of Michigan's Program for Positive Aging, examined more than two decades of scientific studies, along with her coauthors, Laura N. Gitlin and Dr. Constantine Lyketsos, both of Johns Hopkins University. They say the treatments that showed the best results were the ones that trained caregivers how to communicate calmly and clearly, and to introduce hobbies or other activities for the person in treatment. The treatments also followed up with caregivers.

"I think the caregiver interventions work… because they train caregivers to look for the triggers of the symptoms," says Kales. "And when [caregivers] see the triggers of the symptoms, they train them to manage them...It's inherently patient- and caregiver-centered." The study showed that antipsychotic drugs were only about half as effective as the caregiver interventions.

Health care providers use antipsychotics, says Kales, partly because they haven't been trained to use non-drug approaches. And even if they did know how to use them, they're rarely reimbursed for doing so by Medicare or private insurance.[53]

Thus, caregivers need to refocus on interventions that respond to the idiosyncratic needs of the individual. This is sometimes very difficult when the person in treatment is at home, but it is essential to train and support caregivers as well as nursing home staff in psychosocial options that reduce the risks of using antipsychotic medications whenever possible.

As previously stated, a 2015 GAO Report recommended an expansion of U.S. Department of Health and Human Services (HHS) efforts to decrease antipsychotic use, which were initiated in 2012 in nursing homes under the National Alzheimer's Plan.[54] GAO recommended that HHS expand its outreach and educational efforts aimed at reducing antipsychotic drug use among older adults with dementia to include those residing outside of nursing homes by updating the Plan.

Alternatives exist. The GAO recommended emotional therapies and sensory stimulation:

An example of an emotion-oriented approach is Reminiscence Therapy, which involves the recollection of past experiences through old materials with the intention of enhancing group interaction and reducing depression. An example of a sensory stimulation approach is

Snoezelen Therapy, which typically involves introducing the individual to a room full of objects designed to stimulate multiple senses, including sight, hearing, touch, taste, and smell. This intervention is based on the theory that behavioral symptoms may stem from sensory deprivation. A 2012 white paper published by the Alliance for Aging Research and the Administration on Aging, a part of the ACL, noted that advancements have been made with regards to the evidence base supporting some nonpharmacological interventions, but that evidence-based interventions are not widely implemented. Experts referenced in the white paper identified the need for clearer information about the interventions, such as a system to classify what interventions exist and who might benefit from those interventions. Experts also noted that additional research is needed to develop effective interventions.[55]

Educating health care workers reduces the inappropriate use of antipsychotics. A two-day education program in Norwegian nursing homes, followed by a six-month period of monthly group guidance, reduced both the use of restraints and patient agitation. The study included four Norwegian nursing homes housing 145 total residents with dementia, with each home randomly assigned to receive either treatment as usual or an intervention consisting of the two-day educational seminar and monthly group guidance for six months. The co–primary outcome measures were the proportion of residents subject to interactional restraint and the severity of agitation using the Cohen-Mansfield Agitation Inventory (CMAI). The CMAI score declined from baseline to 6 and 12 months' follow-up in the experimental groups compared to a small increase in the control groups.[56]

A study in Northern Ireland utilized specially trained pharmacists, who visited one group of nursing homes regularly over a year and used an algorithm to assess the appropriateness of using psychotropic drugs on residents. By the end of the study, the proportion of residents taking inappropriate psychotropic medications in the experimental group of homes was 19.5 percent, compared to 50.0 percent in the control group.[57]

In another Norwegian study, lowering the dose of antipsychotic medication proved effective in lowering Neuropsychiatric Inventory scores, which measure agitation, apathy, psychosis, and restlessness.[58] And in the same study that utilized the memory test, the residents taken off antibiotics and receiving benzodiazepines or antihistamine hypnotic agents reported more stable or improved anxiety levels over the residents in the control group. At the very least, health care providers, especially those in nursing homes, should regularly monitor and reevaluate elderly patients on antipsychotic medication, and make efforts to stop use or wean off use of them over time.

Anxiolytics

Benzodiazepines are the most common psychotropic drugs taken for anxiety in the United States:

- alprazolam (Xanax)
- chlordiazepoxide (Librium)
- clonazepam (Klonopin)
- clorazepate (Tranxene)
- diazepam (Valium)
- estazolam (Prosom)
- flurazepam (Dalmane)
- lorazepam (Ativan)

- oxazepam (Serax)
- temazepam (Restoril)
- triazolam (Halcion)
- quazepam (Doral)

Although causation has not been established, in 2014, a team of researchers from France and Canada established a convincing link between use of benzodiazepines and the development of dementia. People who had taken a benzodiazepine for three months or less had about the same dementia risk as those who had never taken one. Taking the drug for three to six months raised the risk of developing Alzheimer's disease by 32%, and taking it for more than six months boosted the risk by 84%.[59] Psychiatrists consulted for this position statement all warn that benzodiazepines can exacerbate delusions in anyone with dementia. An FDA WARNING counsels that benzodiazepines are: **"not recommended in the treatment of psychotic patients."** Benzodiazepines are definitely contraindicated in dementia with Lewy bodies, and thus in Parkinson's disease, though the Parkinson's Association only recommends "caution" in Parkinson's dementia.[60]

MHA urges that elders consider use of alternative treatments for anxiety that do not have such cognitive associations. For anyone with dementia, benzodiazepines should be used sparingly, and some psychiatrists avoid using them altogether. Pharmaceutical manufacturers should respond to the challenge of creating a new generation of anxiolytic drugs. Integrative/complementary ("CAM") treatments for anxiety with varying assessments of efficacy include cranial electrical stimulation, rhodiola rosea, valerian, kava (in small amounts to avoid liver toxicity), relaxation techniques and meditation.[61] Cranial electrical stimulation has recently been found in a pilot study to have positive effects on cognition, virtually ruling out that concern.[62] And psychosocial techniques should always be used before trying drug interventions. Validation therapy has an important role in coping with anxiety, as do techniques to refocus the person's attention like hobbies and exercise.

Common drugs like antihistamines and benzodiazepines may exacerbate dementia symptoms in some people under some circumstances and should be used with caution by people with any kind of dementia or mild cognitive impairment. Overall, there is an inadequate evidence base for use of these drugs in older people.

MHA urges much more research and public education concerning the dangers of using anxiolytics and antihistamines in people with dementia. CAM treatments are often a better alternative, with fewer side effects. And again, psychosocial techniques should be emphasized before considering drug therapy and as an essential adjunct if anxiolytics are used.

Effective Period

The MHA Board of Directors adopted this policy on March 5, 2016. It will remain in effect for a period of five (5) years and is reviewed as required by the MHA Public Policy Committee

Expiration: December 31, 2021

1. Thanks for this felicitous phrase are due to Valliant, G.E., Aging Well: Surprising Guideposts to a Happier Life (Little Brown 2002).

2. American Psychiatric Association, Diagnostic and Statistical Manual of Mental Disorders - 5 (American Psychiatric Publishing 2015).

3. Hill, R.D., Positive Aging (W.W. Norton & Co. 2005) quotes Seligman, M.E.P. & Csikszemmihalyi, M, "Positive Psychology: An Introduction," American Psychologist 55:5-14 (2000) in defining the term, focused on well-being, contentment, satisfaction, hope, optimism, and happiness. According to Hill, the traits to be emphasized are: "the capacity for love and vocation, courage, interpersonal skill, aesthetic sensibility, perseverance, forgiveness, originality, future-mindedness, spirituality, high talent, and wisdom." Introduction, at p. xi-xii.

The terminology of "positive aging" is a more recovery-oriented version of the earlier term, "successful aging." Even a person with one or more chronic conditions can age positively -- if not fully successfully. And even "negative aging" is far preferable to "pathological" or "diseased" aging, the terms formerly in use. According to Hill, positive aging has four characteristics: "a person mobilizes resources to cope with age-related decline; a person makes lifestyle choices to preserve well-being; a person cultivates flexibility across the life span; and a person focuses on the positives versus the problems and difficulties of growing old." Id. at 18-23.

4. U.S. Bureau of the Census, "Population Projections of the United States by Age, Sex, Race and Hispanic Origin: 1995-2050, Current Population Reports, P25-1130 (2000).

5. Segal, D.L., Qualls, S.H., & Smyer, M.A., Aging and Mental Health (2nd ed.), (Wiley-Blackwell, 2011), at 7, quoting the CDC (2007). People aged 75 and older actually had less frequent severe symptoms.

6. Padgett, D.K., ed., Handbook on Ethnicity, Aging and Mental Health (Greenwood Press, 1995), at pp. 304-5.

7. See Vickers, R., "Strengths-based Health Care: Self-advocacy and Wellness in Aging," in Mental Wellness in Aging, Ronch, J.L., and Goldfield, J.A., eds. (Health Professions Press, 2003)

8. For more information about wellness programs, see MHA Position Statement 17, Promotion of Mental Wellness.

9. Padgett, supra, at 306. Other groups have not been adequately studied.

10. Id.

11. George, L.K., Blazer, D.G., Winfield-Laird, I., et al., "Psychiatric Disorders and Mental Health Service Use in Later Life," in Epidemiology and Aging, Edited by Brody, J.A. and Maddox, G.L. (Springer, 1988)

12. U.S. Department of Health and Human Services, Older Adults and Mental Health: Issues and Opportunities (Rockville, MD: 2001).

13. See generally, Segal, D.L., Qualls, S.H., & Smyer, M.A., Aging and Mental Health (2nd ed.), supra.

14. Bartels, S.J., Dums, A.R., Oxman, T.E., Schneider, L.S., Areán, P.A., Alexopoulos, G.S. & Jeste, D.V., "Evidence-based Practices in Geriatric Mental Health Care," Psychiatric Services 53(11):1419-1431 (2002). https://ps.psychiatryonline.org/

15. National Association and Mental Health Planning and Advisory Councils, Older Adults and Mental Health: A Time for Reform. DHHS Pub. No. (SMA), Rockville, MD: Center for Mental Health Services, Substance Abuse and Mental Health Services Administration. (2007), no url available.

16. Id.

17. See MHA Position Statement 71, Health Care Reform

18. Muhlestein, D. "Growth and Dispersion of Accountable Care Organizations in 2015," Health Affairs Blog (March 31, 2015, http://healthaffairs.org/blog/2015/03/31/growth-and-dispersion-of-accountable-care-organizations-in-2015-2/

19. Find Geriatric Psychiatrists, U.S. News and World Report Health (last visited January 25, 2016), http://health.usnews.com/doctors/location-index/geriatric-psychiatrists.

20. See https://en.wikipedia.org/wiki/Dementia_with_Lewy_bodies

21. Ginkgo biloba is an ancient Chinese herbal remedy that has been shown to have significant neuroprotective effects, confirmed by all sources. However, two recent major studies and a Cochrane review cast doubt on the validity of the prior, smaller and shorter studies, and determined that in the aggregate the data do not support the use of ginkgo in the prevention of Alzheimer's disease. The recent evidence is mostly negative, though the studies are still inconsistent. Although ginkgo has a mild effect in protecting against mild cognitive impairment/dementia, it probably does not prevent it. But all sources except one remain optimistic for some ongoing neuroprotective role for Ginkgo. /mentalhealthandcam

22. Whitehouse, P.G.. "The Diagnosis and Treatment of Alzheimer's: Are We Being (Ir)Responsible?" Unpublished monograph supplied by and on file with the author (August 19, 2015).

23. Cognitive Aging: Progress in Understanding and Opportunities for Action, The National Academies Press (2015), available for downloading at http://www.nap.edu/download.php?record_id=21693# .

24. Whitehouse, P.J., with George, D., The Myth of Alzheimer's (St. Martin's Press 2008).

25. Whitehouse, P.G., "Taking Brain Health to a Deeper and Broader Level," Neurological Institute Journal, Spring, 17-22 (2010)

26. Id., introduction, at xi.

27. https://vfvalidation.org

28. http://www.guideline.gov/content.aspx?id=43921

29. http://www.tisonline.org/

30. A Consensus on the Brain Training Industry from the Scientific Community, Stanford Center on Longevity (2014)

31. Rather surprisingly, because their scientific foundation was weaker than for cholinesterase inhibitors, a glutamate antagonist, Namenda (memantine), was approved in 2003, but in general its effects are less consistent than those of the cholinesterase inhibitors. Frequently, cholinesterase inhibiters and glutamate antagonists are prescribed together, although the Cochrane Dementia and Cognitive Improvement Group's last review (in 2006) concluded that:

Memantine has a small beneficial, clinically detectable effect on cognitive function and functional decline measured at 6 months in patients with moderate to severe Alzheimer's Disease (AD). In patients with mild to moderate dementia, the small beneficial effect on cognition was not clinically detectable in those with vascular dementia and barely detectable in those with AD.

32. http://www.alz.org/alzheimers_disease_standard_prescriptions.asp

33. Carr, T., "The Hard Truth about Alzheimer's Drugs," Consumer Reports (April 16, 2014), http://www.consumerreports.org/cro/news/2014/04/aricept-exelon-and-razadyne-do-little-to-help-most-people-and-pose-risks/index.htm

34. Daiello, L.A., Ott, B.R., Lapane, K.L., Reinert, S.E., Machan, J.T.& Dore, D.D., "Effect of Discontinuing Cholinesterase Inhibitor Therapy on Behavioral and Mood Symptoms in Nursing Home Patients with Dementia," Am J Geriatr Pharmacother 7(2):74-83. doi: 10.1016/j.amjopharm.2009.04.002 (2009).

35. All Cochrane reviews can be accessed at http://onlinelibrary.wiley.com/cochranelibrary/search

36. http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=306&pageNumber=3

37. M.D., Ph.D., Professor of Neurology and current or former Professor of Psychiatry, Neuroscience, Psychology, Cognitive Science, Bioethics, Nursing, History, and Organizational Behavior, Case Western Reserve University.

38. Whitehouse, P.G.. "The Diagnosis and Treatment of Alzheimer's: Are We Being (Ir)Responsible?" Unpublished monograph supplied by and on file with the author (August 19, 2015).

39. In 2015, Mental Health America began collecting data related to the mental health conditions of people with dementia through its online screening program at www.mhascreening.org.

40. One review links SSRIs with dementia, and speculates: "Contrary to a widely held belief in psychiatry, studies that purport to show that antidepressants promote neurogenesis are flawed because they all use a method that cannot, by itself, distinguish between neurogenesis and neuronal death. In fact, antidepressants cause neuronal damage and mature neurons to revert to an immature state, both of which may explain why antidepressants also cause neurons to undergo apoptosis (programmed death)." The FDA has not required a warning or restricted the label, and anti-depressants are used to treat depression in the elderly. See Andrews et al.,

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CONCLUSION:

"Benzodiazepine use is associated with an increased risk of Alzheimer's disease. The stronger association observed for long term exposures reinforces the suspicion of a possible direct association, even if benzodiazepine use might also be an early marker of a condition associated with an increased risk of dementia. Unwarranted long term use of these drugs should be considered as a public health concern."

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