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WomenAgainstAlzheimer's

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Brain Health is Women's Health

BY WOMENAGAINSTALZHEIMER'S AND THE
NATIONAL ASSOCIATION OF NURSE PRACTITIONERS
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Introduction

In common use, the term "women's health" encompasses practice specialties such as OB/GYN and a consideration of diseases that exclusively or disproportionately affect women, such as breast and cervical cancer. The concept of a "well-woman" examination has become routine in American medicine, is frequently covered by insurance plans for those who have them, and is mandated as a free benefit for plans in the Marketplaces under the Affordable Care Act of 2010.[1]

Yet despite the importance of the well-woman exam and the many benefits it has brought to the health of millions of women, this definition of women's health seems too narrow. Rather, "women's health" should be more broadly considered as encompassing anything relating to the good health of women, including the awareness and treatment of conditions that disproportionately affect women or for which women bear much of the burden, through their own medical history or through caregiving responsibilities (since those responsibilities can affect a woman's own health).

Under this expanded yet necessary definition of women's health, surely brain and memory health falls near the top of the issues raised. We define brain health as the ability to remember, learn, plan, concentrate, and maintain a clear and active mind. Changes to these cognitive functions can help identify early signs of Alzheimer's disease and related dementias.

Indeed, brain health should be considered a vital sign for women's health – and not merely women's health in the aggregate, considering the disease burden in the United States – but even more important, from the perspective of the health of individual women.

There are an estimated 3.3 million women age 65 and older with Alzheimer's in the United States.[2] Millions more will likely develop the disease or other forms of dementia if no cures or additional treatments are found. Others share in bearing the burden of the disease as caregivers for spouses or parents or as family members and friends of those who face the disease and the prospect of life with Alzheimer's. They have legitimate questions as to what Alzheimer's and other forms of dementia are, what treatments are available, how best to care for those suffering from the disease, and whether they might someday have the disease as well. They deserve reliable answers to those questions from the medical system.

The truth is that memory and brain health belong at the forefront of women's health. Women live longer and are thus more at risk for diseases of aging. Women frequently live on their own as seniors and thus need an understanding of the signs of dementia and when they should get assistance. Some women are also at risk for early dementia. Still others often play a significant role in caregiving, including for parents, husbands, and other relatives and thus should be aware of the facts, challenges, and treatment of Alzheimer's disease and other dementias.

Memory and brain health belong at the forefront of women's health.

What is the actual state of women's knowledge about Alzheimer's and other dementias, and what advice is offered to those who inquire about memory health or to those who show symptoms of dementia? To help answer those and other related questions, our organizations conducted a survey of Nurse Practitioners (NPs) to gain impressions of what actually happens in clinical practice.[3]

The survey was broadly-based and includes NPs in community, urban, rural, academic, and other settings. Our goal in conducting it was to determine whether NPs have the information and tools they need to encourage and make timely diagnoses and counsel patients and their families on the road ahead for those diagnosed or at risk for Alzheimer's and other dementias. This included gathering data to learn more about how nurse practitioners currently monitor brain health, conduct memory testing in the patients they see, and make diagnoses of Alzheimer's and related dementias, as well as being able to speak to the "worried well" and to give all women basic information on Alzheimer's and dementia.

At a time when many Americans do not have ready access to physicians, NPs are on the front line of diagnosing, treating, and supporting the estimated 3.3 million women age 65 and older with Alzheimer's in the United States. Their experiences, voices, and referrals are vital to helping women address the growing challenge of Alzheimer's in our society.

While there are some signs of optimism, overall the picture is disturbing, revealing severe challenges that must be overcome to address the growing burden of Alzheimer's and other forms of dementia in the United States today. Both education and treatment, including referrals, need a dramatic step up if women are to have the brain and memory health services they need. American women—and many of the nurse practitioners who serve them—are hungry for more information, more resources, and more access to qualified professionals who can correctly understand and address early symptoms of Alzheimer's and dementia. They deserve no less—and it is time for policymakers and the healthcare system as a whole to take action.

As noted, even though NPs are often on the front line of healthcare and are the providers many women see most often for their wellness, NPs far too often are not initiating conversations about memory, don't know the signs and symptoms of dementia, don't understand the standard screening options, are not confident in their knowledge, and do not fully understand the nexus between diagnosis and clinical trials. Despite the enormous and growing needs of families facing a life with dementia, diagnosis of Alzheimer's and other dementias is often made far too late when patients and their families are already in crisis. Yet because far too few clinicians routinely speak about memory and brain health with the women they serve, too few women are well-informed about Alzheimer's disease and other dementias.

Sources

1 https://www.healthcare.gov/preventive-care-women/

2 The estimates for the number of U.S. women (3.3 million) and men (2.0 million) age 65 and older with Alzheimer's in 2013 is from unpublished data from CHAP. For analytic methods, see: Hebert LE, Weuve J, Scherr PA, Evans DA. Alzheimer disease in the United States (2010-2050) estimated using the 2010 Census. Neurology 2013;80(19):1778-83.

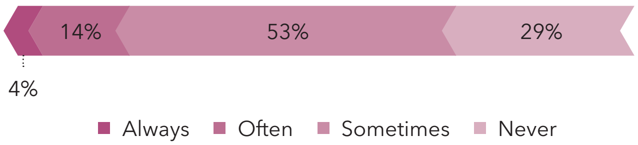
3 Nearly 1000 nurse practitioner members of The National Association of Nurse Practitioners in Women's Health responded to an online survey of 15 questions asking about monitoring brain health in their professional roles, including starting conversations with patients, when patients raised concerns and what steps they take to assess brain health.

Key Findings

Far too few clinical Nurse Practitioners are raising memory issues with their patients.

Close to 30% of NPs report that they never raise memory issues or brain health with patients, and only 18% raise it more than occasionally. Even having personal experience with dementia does not seem to propel NPs to hold these conversations on a regular basis. An important part of the solution is to give NPs the training and tools to better recognize, manage and refer patients who need further assessment, as well as support for conversations about encouraging brain health.

HOW OFTEN DO YOU RAISE THE ISSUE OF MEMORY AND BRAIN HEALTH WITH YOUR PATIENTS?



Patients age 50-70 are most likely to raise memory issues.

In 68% of the cases, patients or caregivers raise memory issues, not NPs. People over 50 increasingly understand that dementia may not just be something that happens in aging, but is caused by neurodegenerative diseases, and they are taking proactive steps to protect their brain health. A majority of NPs want additional resources to help them interpret the signs and symptoms more effectively. Because of the disproportionate impact of dementia on women, NPs in OB/GYN and family planning settings should also know about risk factors for dementia and be discussing them as part of any conversation regarding women's health.

NPs want and need greater access to diagnostic tools.

Scientists are working on new diagnostic tools, and one day we may identify Alzheimer's disease through a simple blood test, but the current methods for diagnosis present a challenge for health care professionals. Almost 10% of the NPs surveyed reported using the Mini-Mental State Examination (MMSE) but there is no standard protocol for cognitive assessment and referral. Tests like the MMSE are only part of the process for diagnosing dementia, and NPs should be sensitive to how individuals experience dementia differently. Making a diagnosis of dementia is often difficult, particularly in the early stages, but is critically important to getting the right support in place.

86% of NPs **do not have** a standard protocol or tool to assess memory problems.

The pathway for what happens following diagnosis or referral is often neither clear, nor consistent.

Many people who are suspected to have some form of dementia receive a referral to a general practitioner or neurologist; some also receive community support. It was not always clear to the NPs we surveyed what the path forward would be for their patients. Establishing a dementia care pathway means starting with knowledge, resources, conversation starters, and easy ways to interact during a quick office visit. Ideally, a person with dementia would have answers to questions regarding future care needs, available support, clinical research opportunities, legal considerations, and any other concerns, so that NPs know when they assess brain health that patients will be getting the support that is right for them.

I WOULD BENEFIT FROM ADDITIONAL RESOURCES AND TRAINING TO HELP ME BETTER SCREEN, MANAGE AND REFER PATIENTS WITH ALZHEIMER'S OR DEMENTIA.

Clinical Practices: Raising the Issue of Memory Health and Referrals

It all starts with the most basic point: having a conversation. Real advances in understanding and treatment of Alzheimer's and other dementias will be difficult to achieve if the issue is not first raised during clinical appointments. Here, the role of NPs is critical. Yet the survey shows that close to 30% of NPs report they never raise the issue, and only 18% raise it more than occasionally. A slim majority (53%) raise the issue sometimes in their practice. Just over 4% always do.

Close to **30%** of NPs **never raise the issue** of brain and memory health in their practice.

Even if one accounts for many NPs treating younger women and practicing in settings focused on OB/GYN, these numbers are shockingly low. Women's health should encompass all factors that affect a woman's health—and her brain health matters greatly to her overall state of health. Even for younger women, raising the issue of brain and memory health early on reaps benefits in terms of patient education and awareness of the proactive steps necessary for brain health, and younger women may also use this knowledge to help inform older relatives or friends who may be facing dementia and encourage them to seek assistance for their memory issues.

Despite the fact that changes in brain health can start more than a decade before active symptoms, a significant percentage of NPs (26%) do not know when to begin asking about brain and memory health during consultations, and more than 50% of NPs surveyed are currently not having any brain health conversations.

Happily, though, *patients* of all ages are increasingly aware of the importance of memory and brain health. When the issue comes up in the appointment, over two-thirds of the time (68%), patients themselves or their caregivers, not NPs, raise the issue. Clinicians raise it only in just over 24% of cases. But patients are hungry for the information and answers that only trained medical professionals can provide.

68% of the time, **patients themselves or their caregivers raise the issue** during the appointment.

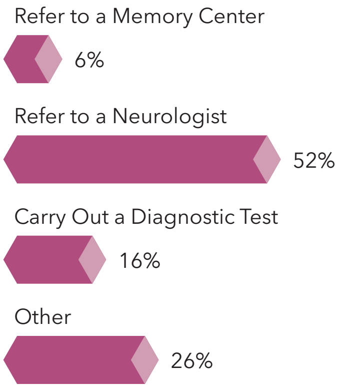
A critical part of NPs' knowledge about memory and brain health is knowing when to refer patients for further screening, where to refer them, and how to do so. If a patient shows signs of memory loss, NPs eagerly take action. Just over half (52%) will refer to a neurologist; 15% will perform a diagnostic test themselves; over 6% will refer to a specialized memory center; and 27% will take other actions, including referral to a primary care physician, referral to a psychiatrist or psychologist who can perform neurological testing, examining for other contributing factors in a patient's medical history, and others.

Of those who are administering a test of some kind, most are using the standard MMSC (Mini-Mental) exam. But nearly 86% of NPs report not having a standard tool or protocol to address memory programs—a very serious situation that demands change given that, for many Americans, NPs are their primary access to the healthcare system.

When a conversation results in the need for further action, for those patients who are referred for screening and care for dementia, NPs utilize a variety of resources. Nearly half (47%) refer to memory specialists; almost as many (42%) refer to community-based organizations, which can be a good source of information and further referrals. Over 21% offer reading materials to their patients, and 17% prescribe medication (in those states where this is permitted by law).

Only 5% of NPs, however, are currently referring their patients for possible participation in clinical trials. This is a missed opportunity to deliver specialized care to patients. While some participants in clinical trials receive placebo rather than the candidate drug, nevertheless it makes no sense for the population served by NPs to be de facto excluded from major clinical trials on important medications that could be breakthrough drugs for people with Alzheimer's and dementia.

IF A PATIENT SHOWS SIGNS OF MEMORY ISSUES OR COMPLAINS ABOUT MEMORY OR DISORIENTATION ISSUES, WHAT PROTOCOL DO YOU USE?



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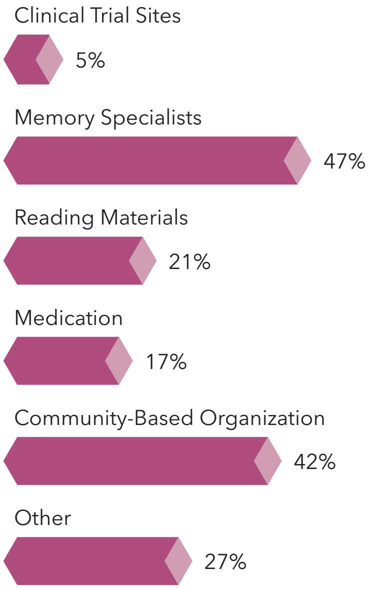


Awareness and Knowledge: Twin Pillars for Change

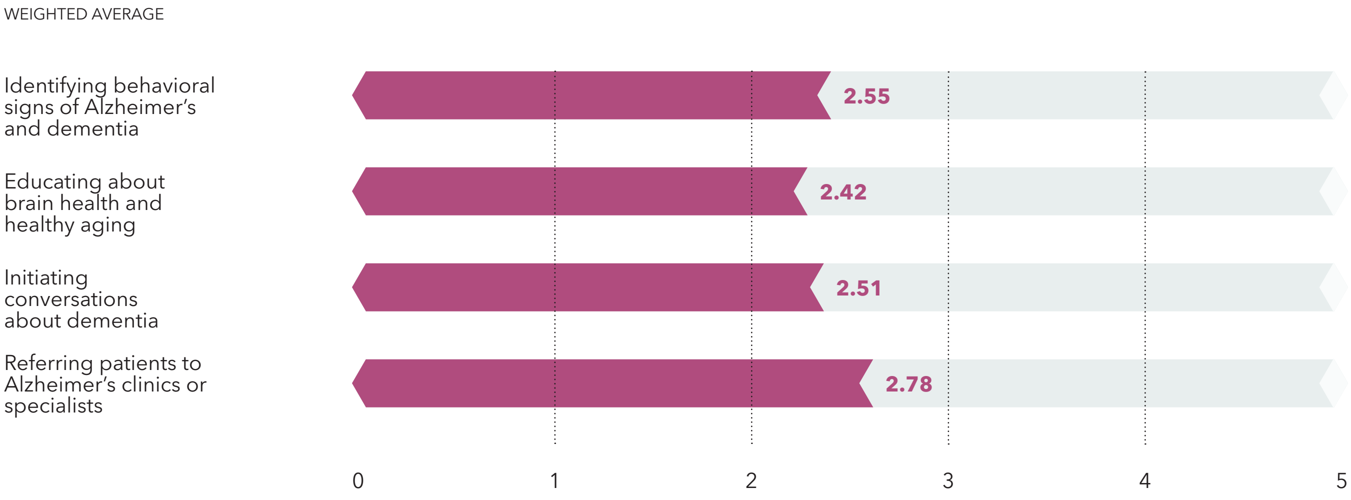
Levels of awareness of Alzheimer's and dementia vary widely among NPs. Unsurprisingly, greater awareness leads to a greater motivation to focus on the conditions. Over half of NPs reported that their personal experience with Alzheimer's or other dementia increases their interest in screening patients for Alzheimer's and other forms of dementia. Add in the one-third who responded that they neither agree nor disagree with the statement (which likely reflects many NPs who work in settings where they do not see many older patients), and personal experience becomes a powerful force for change.

Fortunately, NPs are eager for additional resources and training to help them better screen, manage, and refer patients with Alzheimer's or dementia. Nearly 84% strongly or somewhat agree that they would benefit from additional resources or training in memory and brain health. Some directly responded that, even though they do not have access to screening tools, they would become more confident in speaking with patients about dementia if they had more access to education and resources. They are hungry for information.

Currently, NPs have relatively low levels of confidence in their ability to take steps in their clinical practice to address memory and brain health, including initiating conversations about dementia, identifying behavioral signs of Alzheimer's and dementia, educating patients about brain health and healthy aging, and referring patients to Alzheimer's clinics or specialists.

But this situation can—and must—change through greater resources devoted to training and education for NPs and better coordination among home-based care and community organizations such as senior centers. Our goal is that every facility will be like that which one NP described: "our facility has significant resources including psych/MH APRNs, Neurology specialty services on site," and others. That facility is well-placed to care for those with Alzheimer's and dementia in its community. Every community deserves that standard of care.

PLEASE RATE YOUR CONFIDENCE IN THE FOLLOWING
BASED ON A SCALE OF 1-5, WHERE 1 = "NOT AT ALL CONFIDENT" AND 5 = "VERY CONFIDENT"



Barriers to Progress

In responses to the survey questions, several NPs responded that memory issues "do not apply to my patients." While we appreciate their candor and certainly understand the importance of focusing OB/GYN resources on this important area of women's health, we nevertheless encourage NPs and other clinicians to take a broader approach to women's health—and to take action.

Indeed, some NPs have noted that a 15-minute appointment slot is often not sufficient to address all of a patient's OB/GYN issues, let alone other important issues such as brain health. Over 64% of NPs cite "limited time with patients" as a reason they do not regularly hold conversations with patients about memory concerns or symptoms. This is a broader social and systemic challenge for the healthcare system as a whole, but one key response is to make NPs aware of referral opportunities for memory issues and resources to help their patients understand dementia.

More specifically, a large number of NPs themselves cite barriers to the ability to have conversations about memory health. Over 45% note a lack of familiarity with the signs and symptoms of dementia, over 38% cite a lack of access to neurologists and other dementia specialists, and nearly the same number (37%) report having to address patients' other health issues related to aging in the limited time available during appointments. Over 8% express a concern about language proficiency—another area of concern throughout the healthcare system.

Despite these sobering statistics, particularly about time and access to resources, the good news is that many NPs have thought seriously about what resources would best help them be able to be more proactive with patients, help their patients with signs and symptoms of dementia and move forward with a plan of care.

Most important, nearly 80% of NPs want to have access to a standard protocol they can use for an exam for dementia and a discussion about the test. A majority, 54%, want greater knowledge of the signs and symptoms of dementia, while 49% want help with conversation starters between a patient and her caregiver. Given the role that financing plays in the healthcare system, over 38% would like to have access to a specific code for screening people for dementia, and nearly 36% would like a Medicare wellness checklist to serve their older patients.

Nearly **80% of NPs want a standard protocol** for a dementia exam and a discussion about the test.

Just as the challenges here are large, so the solutions here will be diverse. More access to providers of dementia-related services is critical, but so is access to community-based training and services, preferably at times convenient for busy clinicians to attend, such as on evenings or weekends or through correspondence or online training. Some NPs cited group patient education as a possible model here, as often occurs for diabetic patients or expectant mothers. Bilingual, accessible community resources will play a key role in patient education.

The Path Ahead: A Time for Bold Action

This report is designed to spur action. The social and human cost of Alzheimer's to American women and to American society as a whole is simply too large to ignore. We do not yet have all the answers, even as researchers work tirelessly to find the next breakthrough that will assist in treatment. Solutions will require both top-down approaches—including greater resources, greater involvement of NPs, physicians, and other clinicians—and bottom-up approaches involving empowered and knowledgeable patients and caregivers. But some basic principles for action are clear:

- More Americans need to understand the basics of brain and memory health, including the steps they can take to encourage brain and memory health. The role of clinicians in patient education is vital.
- More clinicians should feel comfortable and knowledgeable introducing brain and memory health issues into their conversations with patients routinely and easily.
- Better referral networks, so that NPs will have access to neurologists and others who can provide more specialized care.
- Clinicians need greater knowledge of how these conversations and referrals will be reimbursed by insurance providers and a much clearer sense of the path ahead for those patients who receive referrals—including referrals to clinical trials.
- Increased referrals by NPs for participation in clinical trials.
- Further study is needed, including studies such as this one with other groups of clinicians to gain understanding of clinical practices and studies of women to gauge their understanding of Alzheimer's and other dementias.

As a society, the United States must take a similar approach to Alzheimer's disease and dementia as happened with breast cancer in the 1980s and Parkinson's disease in the 1990s: greater attention to education, greater sensitivity to the needs of patients, and more generous resources devoted to both research and treatment. For those facing a diagnosis of Alzheimer's and dementia, the path ahead is daunting. They need the consistent and coordinated support of all in the healthcare system with whom they come in contact. NPs can and must play a vital role in bridging the gap between a patient's initial contact with the healthcare system and the specialized referrals and care that patients with Alzheimer's and dementia need. Alzheimer's is the leading cause of death for which there is no cure. The burden falls heavily on American women. This is a time for compassionate care, fresh thinking, and bold action. The healthcare community, including NPs, and patients and caregivers can work together to be catalysts for change.

About Us

WomenAgainstAlzheimer's

WomenAgainstAlzheimer's

As a member of the UsAgainstAlzheimer's Network, WomenAgainstAlzheimer's (WA2) unites women across the globe to find a cure for Alzheimer's.

Our growing network of women is impatient with the slow progress being made in the Alzheimer's fight. Driven by our passion, we are committed to ending current "business-as-usual" approaches to funding, research and advocacy, bringing Alzheimer's out of the shadows and into the spotlight. Because women won't wait.

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Caring for Women

The National Association of Nurse Practitioners in Women's Health

Since its inception in 1980, The National Association of Nurse Practitioners in Women's Health has been a trusted source of information on nurse practitioner education, practice, and women's health issues. The National Association of Nurse Practitioners in Women's Health works with a wide range of individuals and groups within nursing, medicine, the healthcare industry, and the women's health community.

The National Association of Nurse Practitioners in Women's Health's mission is to ensure the provision of quality primary and specialty healthcare to women of all ages by women's health and women's health focused nurse practitioners. Our mission includes protecting and promoting a woman's right to make her own choices regarding her health within the context of her personal, religious, cultural, and family beliefs.

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