

# MICHIGAN DEMENTIA PLAN

Reducing The Burden  
Of Dementia In Michigan



Michigan Dementia Coalition  
Michigan Department of Community Health

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of dementia in Michigan

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Michigan Department of Community Health

August 29, 2003

Ms. Janet Olszewski  
Director  
Michigan Department of Community Health  
320 South Walnut St.  
Lansing, Michigan 48913

Dear Director Olszewski:

It is with considerable pride and anticipation that we present to you and the people of Michigan a plan to reduce the burden of dementia in Michigan. We are hopeful that this plan will lead to improved quality of life for persons with dementia and their caregivers. We are optimistic that the evidence-based, best practice strategies identified in this plan will help reduce the staggering costs of dementia to the state. We are proud that well over a hundred people -- persons with dementia, their care partners, and a broad spectrum of professionals -- have contributed with zeal and passion to the development of this plan.

Alzheimer's disease and dementia began entering the public lexicon just twenty years ago. Now it is one of our most pressing public health issues. Much has changed in twenty years. Many of us remember when most people, including most physicians, believed little could be done for persons with dementia beyond providing a safe environment and comfort care. Now we have proven effective ways to support caregivers, to manage symptoms of persons with dementia, and to prevent unnecessary complications and excess disability. We now have promising pharmacological treatments for cognitive and behavioral symptoms of dementia. Thanks to committed families and professionals, we now have greater insight into the needs of persons with dementia and their caregivers and know how to slow the progression of disability. Maintaining some quality of life for persons with dementia no longer strikes us as a ludicrous concept.

Putting our still rapidly advancing knowledge to work to improve the lives of this most vulnerable segment of society is imperative. We need to use every avenue available to ensure persons with dementia and caregivers receive the support they need to help them in their valiant struggle. ***The great news for Michigan is that giving this support will likely lead to cost savings for the state in the long run.*** As this plan describes, studies indicate that the same measures that improve the quality of life of persons with dementia also ***reduce the costs*** of dementia.

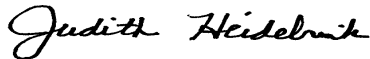
To help ensure implementation of this plan, we ask that the Michigan Department of Community Health:

- Support efforts to implement the plan.
- Include dementia-specific guidelines and coverage in contracts with health care plans.
- Capitalize on the expertise of the Michigan Dementia Coalition by calling upon it for information and expert review of policies and plans when appropriate.
- Review departmental program and service guidelines to ensure that they are dementia appropriate.
- Continue to support funding and regulations that permit the use of Medicaid dollars in the setting of choice.

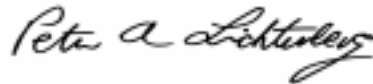
For our part, we are moving ahead even now with this plan and will continue to pursue these goals with the same collaboration and dedication that have been the hallmark of the Michigan Dementia Coalition and dementia stakeholders throughout the state.

The Michigan Dementia Plan Steering Committee expresses our deep appreciation to you and Jan Christensen for your strong support in development of this plan, and for your support for Michigan families, particularly those who are most vulnerable. We look forward to continued partnership in reducing the burden of dementia in Michigan.

Sincerely,



Judith L. Heidebrink, MD  
Co-Chair  
Michigan Dementia Plan Committee  
Michigan Alzheimer's Disease Research  
Center, University of Michigan  
Ann Arbor Veterans Affairs  
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Peter A. Lichtenberg, PhD  
Co-Chair  
Michigan Dementia Plan Committee  
Institute of Gerontology  
Wayne State University

## Leading Organizations

Participants in development of the Michigan Dementia Plan represented many organizations. The following organizations provided leadership.

Geriatric Education Center of Michigan at Michigan State University

Greater Michigan Chapter of the Alzheimer's Association

Institute of Gerontology at Wayne State University

Michigan Alzheimer's Disease Research Center at the University of Michigan

Michigan Department of Community Health, Public Health Administration, Chronic Disease and Injury Control Division

Michigan Great Lakes Chapter of the Alzheimer's Association

Michigan Public Health Institute, Health Promotion and Disease Prevention Program

North/West Michigan Chapter of the Alzheimer's Association

Pine Rest Christian Mental Health Services

# Michigan Dementia Plan

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# Executive Summary

Of all the conditions that threaten the public health, dementia may have the broadest impact. Dementia affects the mind, body and “soul,” and it affects the life of the primary caregiver as much or more than the person with the condition. In Michigan, an estimated 200,000 persons have dementia. Considering its profound impact on caregivers, dementia thus affects at least 400,000 people in our state. With the aging of the population, providing care to someone with dementia is an increasingly normative life experience.

The costs of dementia to Michigan are staggering. Alzheimer’s disease, the most common cause of dementia, is the third most expensive disease in the country. At an estimated cost of \$25,000 per person per year, the financial burden of dementia in Michigan is about \$5 billion per year. Persons with dementia may also experience potentially modifiable complications, including depression, injuries, infections, pneumonia, chronic skin ulcers, and malnutrition. Caregivers have a higher rate of depression and stress than non-caregivers. Many caregivers neglect their *own* health until their health problems cannot be ignored, further adding to the costs attributable to dementia.

Evidence indicates that support for caregivers and implementation of proven dementia care guidelines help to delay or prevent loss of function and progression to higher, more costly levels of care. Key elements of support for caregivers include awareness of community services, respite from caregiving, and education. Key elements of effective dementia care include identification of patients at risk, early recognition of symptoms, referral of patients to specialists and community resources, and increased use of palliative care in place of unwanted and expensive measures at the end of life.

This plan is the culmination of a process designed to identify the best strategies to decrease the burden of dementia in Michigan. The process began with three community forums on dementia in Lansing, Marquette, and Gaylord in October, 2002. More than sixty people – persons with dementia, caregivers, and dementia experts – presented their perspectives on the problems dementia poses and effective ways to address these problems. A number of additional persons provided written input.

The Michigan Dementia Coalition convened a State Dementia Plan Committee of more than fifty individuals in December, 2002, to discuss the community forum findings, begin setting priorities among the needs, identify potentially effective strategies, and establish key goals. In their respective subcommittees, State Dementia Plan Committee members continued to develop and prioritize strategies with feedback from the Michigan Dementia Coalition, the Michigan Primary Care Physicians Dementia Leaders Network, and others.

The Michigan Dementia Plan represents the combined best thinking of more than one hundred persons in Michigan who care deeply about dementia and its impact on individuals, families, and the state. The plan is strategic rather than comprehensive. We are confident that investment in these strategies will pay handsome dividends.

Five goals, and strategies to achieve them, comprise the plan:

**1. Increase support for family members who provide care for persons with dementia at home.**

- Identify and promote the adoption of flexible, innovative respite care programs that respond to the diverse and changing needs of persons with dementia and their families.
- Establish a Michigan Dementia Coalition and Office of Services to the Aging work group to address dementia issues in respite services.
- Increase use of telephone-based interventions designed and documented to strengthen caregivers' skills in managing the challenges of caring for a person with dementia.
- Promote ongoing training to increase family caregivers' skills in communicating with physicians.

**2. Promote a public health, disease management approach to dementia care in primary care practice that makes full use of best dementia care practices.**

- Equip the Michigan Primary Care Physicians Dementia Leaders Network to implement its plan by developing the network infrastructure.
- Link and develop centers of dementia assessment, diagnosis, and clinical best practices.
- Demonstrate community models of dementia best care practices.

**3. Increase the dementia competency of health care professionals.**

- Design and implement an initiative to increase dementia training in formal professional education programs.
- Include dementia-specific requirements in continuing professional education requirements.

**4. Improve the choices for residence and care of persons with dementia.**

- Inform policymakers of the importance and benefits of enabling persons with dementia to live in the care setting of choice.
- Advocate with policymakers for a long-term care reimbursement model in which care in the least restrictive environment, including one's own home, is financially viable.



**5. Increase early intervention by increasing public awareness of the caregiver role and the early warning signs of dementia.**

- Develop and implement a multi-phase public education campaign based on best practices in social marketing.

Persons with dementia are among the most vulnerable segments of our society. Human decency requires that, as a state, we serve them well and do all within our means to secure for them the best quality of life possible, despite the limitations of dementia. We should “do the right thing” for people with dementia. Emerging evidence indicates that doing the right thing for people with dementia will not only improve their quality of life and that of their care partners, but will also save the state and the health care system costs in the long run.

# Introduction

Dementia's impact on individuals, families, communities, and health care costs exceeds that of most other chronic diseases and conditions. In the mid-1980s, Michigan recognized dementia as an emerging issue and began to develop strategies to respond to growing needs. The work of the first state task force laid the foundation for a range of programs and services that have grown since then, and Michigan has become a leader among states in addressing the needs that dementia imposes.

In the years since the first state planning process on dementia, there have been dramatic changes in the knowledge of dementia and the diseases that cause it, as well as in chronic disease management and effective methods of caregiver support. At the same time, dementia-related needs have continued to grow along with the population of persons with dementia. The expanding knowledge base, increasing need, and an impending public health crisis in dementia—all in the face of shrinking resources—created a sense of urgency to take a fresh and comprehensive look at dementia programs and services in Michigan and, from this review, develop a new state dementia plan with a public health approach.

In 2002, the Michigan Dementia Coalition began development of the new state dementia plan. Families living with dementia and other stakeholders across Michigan were an integral part of the process. In October 2002, three public hearings brought together persons with dementia, families, and professionals to share their perspectives, insights, and priorities. They pleaded for expansion of programs, services, and financial aid to help alleviate the heavy burden that dementia imposes. Their voices resonate throughout this plan.

We were tempted to try to address all of the expressed needs. We resisted that temptation, knowing that, despite the compelling needs, funding for a comprehensive plan would not be possible at this time. Michigan is currently wrestling with one of the most difficult economic climates in its history. Dollars simply do not exist to implement a plan that *comprehensively* addresses dementia needs throughout the state, even though this approach could lead to greater savings in the long run. This plan, then, represents a *strategic* approach to decrease the burden of dementia as much as possible with a modest increase in funding. The plan represents the carefully selected and honed strategies that the Michigan Dementia Coalition, with support from the Michigan Department of Community Health, will implement in order to reduce the burden of dementia in Michigan. The Michigan Dementia Coalition will use the priorities set forth here to guide its efforts in the coming three to five years.

To those who provided statements—verbal or written—at the community forums, we want to assure you that we took into consideration the entire array of concerns and requests. While this plan focuses on many, but not all, of the needs identified, we trust you will agree that the strategies chosen have a high probability of success and that you will witness their effectiveness in the years to come.

In submitting this plan to the Michigan Department of Community Health to enlist its support, we invite other dementia stakeholders throughout Michigan to join us in focusing on these strategies and priorities. Managed care organizations, human and social services providers, businesses, faith organization leaders, community leaders, local governments, and schools can help. Those who have dementia are your patients, your clients, your employees, the mothers or fathers of your employees, your parishioners, your taxpayers, and the grandmothers and grandfathers of your students. And someday, too soon, it will be some of us.

Great challenges present great opportunities. The greatest savings can be found where the greatest costs are incurred. We believe that implementation of this strategic plan will help Michigan save on future health care costs and will go a long way toward alleviating some of the suffering of persons with dementia and their care partners throughout Michigan.

# Background

## Defining dementia

Dementia is an impairment in thinking abilities that persists long enough and is severe enough to interfere with daily function. In other words, dementia is the condition that exists when the brain fails to do its work.

Dementia encompasses many symptoms that indicate a decline in thinking skills. Common symptoms of dementia include loss of memory, problems with reasoning or judgment, disorientation, difficulty learning, loss of language skills, and a decline in ability to perform routine tasks. Dementia also affects personality and may cause depression, agitation, anxiety, misperceptions, or hallucinations.

Although the majority of persons who experience dementia are over age 65, dementia is not a normal part of the aging process. Rather, it is the result of one or more illnesses or disease processes that affect the brain. It is a chronic condition, and a number of chronic diseases may cause it. Alzheimer's disease is the most common cause of dementia, particularly in the elderly. Strokes (vascular dementia) are another frequent cause. Other underlying diseases are dementia with Lewy bodies, frontotemporal dementia, Parkinson's disease, Huntington's disease, multiple sclerosis, and Creutzfeldt-Jakob disease. In young adults, head injury is a leading cause of dementia.

Some conditions that mimic or worsen dementia are reversible. For example, impairments of brain function due to thyroid problems, vitamin deficiencies, or medication side effects can be reversed with treatment. Most dementias, however, are not reversible. Even when irreversible, treatment may stabilize symptoms or slow progression. Assessment to determine the specific cause of dementia is important to ensure that persons receive the best treatment available.

Dementia is similar to other chronic conditions and diseases in that management of symptoms and ongoing patient care are extremely important. Dementia requires ongoing physician involvement to retain as much quality of life as possible for those affected and their caregivers, and to minimize unnecessary disability, complications, and suffering. Dementia differs from many chronic diseases in that patient education and self care must be translated into care partner or caregiver education.<sup>1</sup> Caregivers become partners in care with their loved ones and with physicians.

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<sup>1</sup> Some persons object to the term caregiver as inappropriate in situations where persons with dementia retain self-care abilities. Particularly when dementia is identified early, it may be more appropriate to refer to the person who assists in care as the care partner. In this document, we primarily use the term caregiver since that is the term generally used in literature, but we urge sensitivity to choice of terms.

## The burden of dementia in Michigan

Dementia devastates individual lives and wreaks havoc on the state's economy. We estimate that 200,000 people in Michigan have dementia.<sup>2</sup> Considering its profound impact on care partners and other close friends and family members, it is realistic to think of dementia as *affecting* 400,000 persons in Michigan: the person with the condition and at least one primary caregiver. At present, an estimated 4 million people in the U.S. currently have Alzheimer's disease, the most common form of dementia.<sup>3</sup> In general, the percentage of people with Alzheimer's disease and related dementias doubles every five years after age 65. As many as half of people age 85 and over have Alzheimer's disease. With the increase in life expectancy and the aging of the Baby Boomer generation, the number of elderly persons with dementia is on the verge of burgeoning growth.

The personal toll of dementia on persons who have the condition and family caregivers cannot be calculated. They experience direct costs (medical care), indirect costs (such as lost wages from missed work), and the incalculable costs of emotional and physical pain and suffering.

The financial burden of dementia is enormous. Alzheimer's disease is the third most expensive disease in the United States, after heart disease and cancer. The economic impact of Alzheimer's disease and other dementias is greater than the cost of diabetes, stroke, or HIV/AIDS.<sup>4</sup> The U.S. spends at least \$100 billion a year on Alzheimer's disease,<sup>5</sup> which translates to about \$25,000 per person, per year. Under the assumption that other types of dementia have similar costs, Michigan faces a financial burden for dementia of about \$5 billion per year.

Other aspects of the impact of dementia on health care costs:

- Direct medical costs for Alzheimer's disease are approximately \$6,000 per patient, per year.<sup>6</sup> Annual medical costs for vascular dementia are substantially higher.<sup>7</sup>
- A recent study estimated the annual cost of caring for someone with Alzheimer's disease ranges from \$18,400 for a mild case, to \$30,000 for a moderate case, to \$36,000 for someone with severe disease.<sup>8</sup>

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<sup>2</sup> Many factors make estimation of the prevalence of dementia difficult; among them are the challenges of definition and measurement. The Alzheimer's Association estimates that there are 167,600 people in Michigan with Alzheimer's disease, the most common cause of dementia. Another estimated 6,000 people in Michigan have dementia due to Parkinson's disease and nearly 1,000 due to Huntington's disease.

<sup>3</sup> National Institute on Aging. *2001-2002 Alzheimer's Disease Progress Report*. Washington, D.C.: NIA, 2003.

<sup>4</sup> National Institutes of Health. *Disease-Specific Estimates of Direct and Indirect Costs of Illness and NIH Support*. Washington, D.C.: NIH, February 2000.

<sup>5</sup> Leon J, Cheng C, Neumann P. Alzheimer's disease care: Costs and potential savings. *Health Affairs*. 1988;17:206-16.

<sup>6</sup> Taylor DH Jr, Sloan FA. How much do persons with Alzheimer's disease cost Medicare? *J Am Geriatr Soc*. 2000 Jun; 48:639-46.

<sup>7</sup> Fillit H, Hill J. 2002. The costs of vascular dementia: a comparison with Alzheimer's disease. *J Neurol Sci*. 2002;15:203-204:35-9.

- In a study of Medicare claims, the Centers for Medicare and Medicaid Services found that Medicare expenditures for people with Alzheimer’s disease are nearly three times higher than the average for all beneficiaries.<sup>9</sup>
- Nearly 60% of nursing home residents are there because they have dementia. They tend to have the longest nursing home stays and are among those most likely to “spend down” to Medicaid.<sup>10</sup>
- People with Alzheimer’s disease and other dementias may develop complications that drive up the cost of health care. These include pneumonia, malnutrition, septicemia, hip fracture, non-fall-related injuries, and chronic skin ulcers. A study of people age 72 and older found that the average healthcare cost of a fall injury was \$19,440.<sup>11</sup>
- Caregiving contributes directly to higher health care costs. One in eight Alzheimer’s disease caregivers becomes ill or injured as a direct result of giving care.<sup>12</sup> Compared to non-caregivers, they have poorer immune function, slower wound healing, poorer response to flu vaccines, and more respiratory tract infections.<sup>13</sup> Depression among caregivers is three times the norm for their age group.<sup>14</sup>

In addition to health care costs, dementia affects the economy through its impact on businesses. Most people who care for elderly loved ones also work full time. Conflicting work and caregiving demands lead to increased business costs. These costs are related to replacing workers who leave their jobs, workday interruptions, care recipient crises, partial and total absenteeism, and special demands on supervisor time. In “The Toughest Thing I’ve Ever Done,” the author tells the story of Michele Ochsner, who “tried desperately to look after her aging parents—both of whom had Alzheimer’s—from 1,200 miles away” while holding a research job at Rutgers University.<sup>15</sup> In 2002, the estimated annual cost of Alzheimer’s disease to businesses nationwide was \$61 billion.<sup>16</sup> Extrapolating these costs to dementia in general, the annual cost to businesses in Michigan is more than \$3 billion.<sup>17</sup>

At the office, “I was physically present, but I was really preoccupied... It really did dominate my life for a couple years.”  
Michele Ochsner<sup>15</sup>

<sup>8</sup> Alzheimer’s Association website: [www.alz.org](http://www.alz.org) April 18, 2003.

<sup>9</sup> Centers for Medicare and Medicaid Services, FY 2000 Medicare claims data as reported by the Alzheimer’s Association website: [www.alz.org](http://www.alz.org) April 18, 2003.

<sup>10</sup> Alzheimer’s Association. Centers for Medicare and Medicaid Services Minimum Data Set Cognitive Performance Scale as reported in the Alzheimer’s Association *2003 National Public Policy Program to Conquer Alzheimer’s Disease*. Chicago: Alzheimer’s Association; 2003.

<sup>11</sup> Stevens JA. Falls among older adults: Public health impact and prevention strategies. In *Falls and Fall-related Injuries, Special Report of the Journal of the American Society on Aging*. Winter 2002;03:7-14.

<sup>12</sup> National Alzheimer’s Association, [www.alz.org](http://www.alz.org) July 31, 2003.

<sup>13</sup> Research of J Kiecolt-Glaser and R Glaser, reported in The high cost of caregiving, *Mind/Body Health Newsletter*, 1998,7;3:4.

<sup>14</sup> U.S. Department of Health and Human Services Administration on Aging, Family Caregiver Fact Sheet: The Many Faces of Aging, [www.aoa.org](http://www.aoa.org), May 2001.

<sup>15</sup> McGregor, J. The toughest thing I’ve ever done. *Smart Money*, December 2000: 120-125.

<sup>16</sup> Koppel R. *Alzheimer’s Disease: The Costs to U.S. Businesses in 2002*. Social Research Corporation, 2002.

<sup>17</sup> \$61 billion divided by 4 million persons equals \$15,250 per person with Alzheimer’s disease.

## Progress and achievements to date

Twenty years ago, Michigan identified dementia as an emerging issue and began to tackle the most salient needs. A governor's task force in 1986 and a joint legislative committee in 1987 carried out the first planning process. Several state-level groups helped design and implement components of an initial state dementia plan. These groups include the Michigan Department of Public Health Chronic Disease Advisory Committee; the Mental Health and Aging Advisory Council; the Human Service Directors Work Group on Long Term Care; the Alzheimer's Disease Demonstration Grant to States Program Advisory Group; and the Michigan Dementia Coalition and its predecessor, the Dementia Services Coordinating Council.

The following highlights attest to the achievements since this first state planning process:

- Voluntary health organizations for people with Alzheimer's, Huntington's, and Parkinson's diseases rapidly developed and have continued to expand and enhance information, education, and support services.
- The state developed policies and programs to improve the availability, access, and quality of home care and community services to address the needs of people with dementia and their families.
- Legislation designated people with dementia as a subset within mental health services and the long-term care system.
- Voluntary health organizations implemented statewide toll-free helplines and respond to thousands of calls each year. In the past five years, annual helpline calls have increased from 2,400 to 16,000 per year.
- Specialty centers and institutes within the University of Michigan, Eastern Michigan University, Michigan State University and Wayne State University have advanced our knowledge and understanding of dementia through state-of-the-art research and education.
- The Michigan Dementia Education Network was established and provides ongoing educational opportunities for dementia trainers around the state, who in turn offer training for families and professionals.
- The recently formed Primary Care Physicians Dementia Leaders Network has identified ways to enhance the dissemination of dementia best care practices throughout the state.

As I look at what Michigan has accomplished in the past 20 years to assist those with dementia and their families, I am both proud and determined. I'm proud of the state's accomplishments, and determined to make Michigan a leader in the future. We want Michigan to be a place where every person with dementia and every care partner of a person with dementia feels surrounded by a caring and supportive community.

Janet Olszewski

Director, Michigan  
Department of Community  
Health  
May 20, 2003

Today, a range of programs and services in Michigan help to meet the needs of persons with dementia and their caregivers. Of particular note are the Michigan Dementia Coalition and state programs specifically for persons with dementia or for populations that include persons with dementia. The Michigan Department of Community Health and the Office of Services to the Aging administer funds for these programs.

The **Michigan Dementia Coalition** is a vital coordinating center for the broad spectrum of professionals and organizations in the field of dementia. It represents a diverse group and a unique collaboration of consumers, community groups, universities, and government units working to improve the quality of life of persons with dementia and their families in Michigan. Participants share information, identify opportunities to coordinate efforts, provide recommendations as appropriate to the Michigan Department of Community Health, and seek meaningful ways to influence dementia awareness, policy, and service development in Michigan. Core members of the Michigan Dementia Coalition are

- Michigan's three chapters of the Alzheimer's Association
- The Huntington's Disease Society of America – Michigan Chapter
- The Michigan Parkinson Foundation
- The Michigan Alzheimer's Disease Research Center at the University of Michigan

Other universities represented on the Coalition include Eastern Michigan University, Michigan State University, Wayne State University, and Western Michigan University. Participating state government units are the Michigan Department of Consumer and Industry Services; the Michigan Department of Community Health Community Public Health Administration; the Michigan Department of Community Health Bureau of Mental Health, Substance Abuse and Long Term Care Programs; and the Office of Services to the Aging.

Through the **Community Public Health Administration**, \$440,000 annually funds the Michigan Public Health Institute (MPHI) dementia program. This program coordinates the Michigan Dementia Coalition, staffs Coalition initiatives, and contracts with the Alzheimer's Association Chapters, the Huntington's Disease Society of America – Michigan Chapter, and the Michigan Parkinson Foundation for statewide toll-free helplines and other information, referral, and assistance services.

MPHI contract agencies work together as the Dementia Information Network to maximize effectiveness of their services. In 2002, network agencies responded to more than 16,000 helpline callers and provided follow-up calls or services to about half of the callers. In addition, the network provided 575 educational presentations for families and 340 for professionals; sponsored nearly 2,500 support group meetings in 270 locations; disseminated approximately 230,000 newsletters; and maintained 187 resource lending libraries around the state.<sup>18</sup>

In the **Bureau of Mental Health, Substance Abuse and Long Term Care Programs**, the Division of Long Term Care Programs is responsible for planning and implementing

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<sup>18</sup> Michigan Department of Community Health funds provide partial support for the information, education, referral, and support services of the Dementia Information Network agencies.



reforms in home-, community-, and facility-based programs for Michigan's Medicaid populations in need of long-term care support. People with Alzheimer's disease make up one of the four target groups for whom improvements in quality of care and quality of life are proposed. The division also administers the MI CHOICE Medicaid Waiver Program for Elderly and Disabled Adults, and administers the Alzheimer's Demonstration Grant to States Program grant project in Michigan.

The Division of Community Services / Mental Health, Service Innovation and Consultation Section administers dementia-capable caregiver education and respite programs with funding for Older Adult Mental Health Initiatives. The Alzheimer's Caregiver Education Programs offer families and professional caregivers geographic access to community-based educational programs. These programs are designed to increase caregiver knowledge about dementing illnesses as well as provide concrete support and services to help affected individuals retain their abilities and participate in meaningful activities of daily living. Many of the individual programs are organized in collaboration with chapters of the Alzheimer's Association and other professionals and educators knowledgeable about dementia care. About 5,000 people participate in caregiver education programs each year. The Alzheimer's Respite Programs are coordinated on a regional basis through Community Mental Health Service Programs in partnership with provider networks of local aging, public health, community action, and home health agencies. Respite program personnel are trained to know how to work with people who have dementia. Services may include adult day care, group or in-home respite care, and ancillary support services, such as caregiver information, education, and crisis intervention. Approximately 600 families receive respite services each year.

The **Office of Services to the Aging** is the state focal point for older adult services. Michigan has about 1.6 million people over the age of 60. With both federal and state legislation, funding, and mandates, the Office of Services to the Aging oversees Michigan's network of 16 regional Area Agencies on Aging and many local community-based agencies that offer services to older adults. All funded aging services are available to persons 60 years of age or older who meet program eligibility criteria; this includes many people with dementia and their caregivers. In 2002, a budget of \$91 million supported a wide range of services throughout the state. In the same year, \$36.8 million of state and federal nutrition funding provided 12,002,714 meals; over 8.4 million meals were delivered to 55,150 older adults in their homes and more than 3.5 million meals were provided to 53,705 people in congregate meal programs.

In 2001 (last available data), more than 5,500 caregivers received 895,102 hours of respite care and an additional 1,274 caregivers received 381,068 hours of adult day services. This represents an 87% increase in respite services and 236% increase in adult day services since 1999. In addition, a significant number of new adult day care service programs have been developed and existing programs have increased their service capacity.

## What more can be done now?

Our knowledge about dementia has exploded over the past decade. We have a much better understanding of how dementia affects individuals and how to preserve the quality of their lives. Care partners no longer need to rely on a single handbook of care—*The 36 Hour Day*,<sup>19</sup> but can choose from an array of excellent care guides, such as *The Best Friends Approach to Alzheimer's Care*,<sup>20</sup> *There's Still a Person in There*,<sup>21</sup> and other insightful and practical publications.

Alzheimer's demonstration projects across the country and in Michigan have advanced best practices in caregiver education and support. Expert panels have developed clinical practice guidelines for the recognition of dementia and the diagnosis and management of the symptoms of Alzheimer's disease and related disorders. Emerging research is showing the potential for best practices and effective interventions to lead to substantial cost savings. Authors of a study of patients in thirteen sites across nine states assert:

*Our data also imply that cost savings in the care of Alzheimer's patients are potentially large. Our data show that interventions that lead to improvements in memory and physical functioning or that delay the rate of decline could lead to cost savings for both formal and informal care.*<sup>22</sup>

Documented ways to reduce the personal and financial burdens of dementia include:

- Delay the progression to higher levels of care as long as possible without compromising quality of life. Delaying nursing home admission for people with Alzheimer's by just one month could save at least \$1.12 billion a year.<sup>23</sup>
- Identify dementia early and provide ongoing care management. This may help reduce costs associated with pneumonia, chronic skin ulcers, infection, depression, behavioral disturbances, hip fracture, malnutrition, dehydration, intestinal obstruction, lacerations, sprains, hypothermia, and burns.<sup>24</sup>
- Provide support to caregivers. The stress of caregiving can be fatal: there is evidence that caregiving is an independent risk factor for mortality.<sup>25</sup> Simple caregiver interventions such as counseling and supportive services have

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<sup>19</sup> Mace N, Rabins P. *The 36-Hour Day: A Family Guide to Caring for Persons with Alzheimer's Disease, Related Dementing Illnesses, and Memory Loss in Later Life*. Chicago: Johns Hopkins University Press, 1981.

<sup>20</sup> Bell V, Troxel D. *The Best Friends Approach to Alzheimer's Care*. Baltimore: Health Professions Press, 1997.

<sup>21</sup> Castleman M, Gallagher-Thompson D, Naythons M. *There's Still a Person in There: The Complete Guide to Treating and Coping with Alzheimer's*. New York: The Berkley Publishing Group, 1999.

<sup>22</sup> Leon J, Cheng C, Neumann P. Alzheimer's disease care: Costs and potential savings. *Health Affairs*. 1998;17:206-16.

<sup>23</sup> Alzheimer's Association website: [www.alz.org](http://www.alz.org), February 12, 2002.

<sup>24</sup> Ibid.

<sup>25</sup> Schulz R, Beach SR. Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. *JAMA*. 1999;282(23):2215-9.

demonstrated almost a year's delay in nursing home placement over the eight years of an ongoing study of caregiver interventions for persons with dementia.<sup>26</sup>

- Treat cognitive symptoms. Studies have shown that drug therapy has a positive effect on cognition and can reduce overall health care costs.<sup>27</sup>
- Treat behavioral symptoms. Behavioral symptoms increase the cost of care and lead to institutionalization.<sup>28</sup>
- Provide palliative care for persons with advanced Alzheimer's disease. Avoiding costly and unwanted late-stage interventions may save \$7,000 per patient,<sup>29</sup> or up to 70% of the cost of traditional end-of-life care.<sup>30</sup>

## **Community forum findings and development of the Michigan Dementia Plan**

The Michigan Dementia Plan proposes strategies that the Michigan Dementia Coalition will pursue in partnership with the Michigan Department of Community Health. More than one hundred people contributed to the Plan's development (see Appendices A and B). The Michigan Dementia Coalition began the process by soliciting community input from all those concerned about dementia in Michigan. In October 2002, the Coalition held community forums (see Appendix C) in three locations to gather testimony statewide regarding the unmet needs of persons with dementia and their families, and the strengths and weaknesses of current programs and services.

Participants of the community forums reminded us of the problems faced by persons with dementia, in addition to losing the ability to think and remember. Persons with dementia:

- Are regarded by many as having little worth
- Are sometimes taken advantage of or exploited
- Are rarely given a voice in their own care and activities
- Rarely have their remaining abilities recognized or encouraged
- Rarely encounter someone able to communicate effectively with them
- Often have multiple other health problems

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<sup>26</sup> Alzheimer's Association. Alzheimer's Disease Centers: an infrastructure for research, caregiver assistance. *Advances* 2000;20(2):1-2.

<sup>27</sup> Meek P, McKeithan DK, Schumock GT. Economic considerations in Alzheimer's disease. *Pharmacotherapy*. 1998; Mar-Apr;18(2 Pt 2):68-73.

<sup>28</sup> Murman DL, Chen Q, Powell MC, Kuo SB, Bradley CJ, Colenda CC. The incremental costs associated with behavioral symptoms in AD. *Neurology* 2002;59:1721-1729.

<sup>29</sup> Fitch K, Pyenson B. *Value of Hospice Benefit to Medicaid Programs*. Report commissioned by the National Hospice and Palliative Care Organization. New York: Milliman, U.S.A., Inc. 2003.

<sup>30</sup> Studies of various palliative care populations yield a range of statistics on the cost savings of palliative care. One study of cancer patients in a town in Spain found a 71% increase in the cost per patient in standard care compared to home care. See Serra-Prat M, Gallo P, Picaza JM. Home palliative care as a cost-saving alternative: evidence from Catalonia. *Palliat Med* 2001;15:271-278.

- Frequently experience additional problems due to multiple, inadequate, or inappropriate medications
- Often experience depression that is unrecognized and untreated
- May be neglected, especially if living alone
- May be abused
- Sometimes have their legal rights neglected
- Often do not have adequate opportunities for socialization
- Often lack transportation
- Often encounter health and service providers who do not understand their personal history and culture
- Often lack options for places to live that maintain and nurture their quality of life
- Often do not have adequate finances to cover the cost of support and care
- Often deteriorate with inadequate care regardless of the setting – home, adult foster care home, assisted living facility, nursing home, hospital

Community forum participants gave witness as well to the difficulties experienced by those who care for loved ones with dementia. These include:

- Isolation from former friends and family
- Depression
- Poor health
- Exhaustion
- Lack of emotional support
- Lack of awareness of available resources to assist
- Lack of knowledge of ways to cope
- Inadequate finances
- Lack of accessible, affordable, and appropriate respite
- Lack of accessible, affordable, home-like, quality residential care options for their loved one
- Difficulty obtaining a diagnosis for their loved one
- Difficulty finding crisis care for their loved one

Other related problems cited by forum participants:

- Families' denial of the presence of dementia in a loved one prevents them from getting needed help.
- Health care providers, including family physicians, may not realize how much can be done to assist families coping with dementia.
- Health care providers, formal caregivers, and community service providers across professions and institutional settings often lack competence in interacting with and serving persons with dementia.
- Some families and professionals are confused about the appropriate roles of agencies and health professionals.
- Medicare and other insurance programs do not provide adequate coverage for diagnosis, treatment, and care of persons with dementia.
- Dementia is not recognized as a chronic condition requiring ongoing management.

- Accountability of assisted living facilities and adult foster care homes is lacking.
- Many families and health care providers are unaware of the availability of hospice for end-stage dementia patients.
- Michigan lacks adequate outreach and services for minorities.

In December 2002, following the public forums, the Michigan Dementia Coalition convened a State Dementia Plan Committee with three subcommittees to look at the expressed needs and explore ways to respond to them. The three subcommittees were Persons with Dementia and Their Caregivers, Health Care, and Public Awareness and Public Health.

The State Dementia Plan Committee carefully studied both needs and strategies to address them. Given the present state of the economy in Michigan, the Committee believed that proposing a plan that tried to comprehensively address all needs would be unrealistic. Thus the committee carefully considered strategies that were evidence-based, capitalized on existing resources, and could be implemented affordably to create the greatest impact.

With these criteria in mind, the committee identified five priority goals and strategies to achieve them. Michigan Dementia Coalition members, members of the Michigan Primary Care Physicians Dementia Leaders Network, and others provided input throughout this process.

The five goals and strategies to reach them constitute the Michigan Dementia Plan to reduce the burden of dementia in our state. Combined, they are likely to have the greatest impact on the quality of life of individuals with dementia, on the quality of life of caregivers, and on the health care systems serving them. The goals and strategies are presented in the sections that follow. Each section includes an overview of the problems relevant to the goal, a discussion of known effective approaches, and the proposed strategies.

# Goals and Strategies

## Caregiver Support

**Goal 1: Increase support for family members who provide care for persons with dementia at home.**

### Strategies:

- **Identify and promote the adoption of flexible, innovative respite care programs that respond to the diverse and changing needs of persons with dementia and their families.**
- **Establish a Michigan Dementia Coalition and Office of Services to the Aging work group to address dementia issues in respite services.**
- **Increase use of telephone-based interventions designed and documented to strengthen caregivers' skills in managing the challenges of caring for a person with dementia.**
- **Promote ongoing training to increase family caregivers' skills in communicating with physicians.**

Throughout Michigan, family caregivers are beginning to define how respite care can best meet their needs. The standard option of respite care from 7 to 7 Monday through Friday is only one viable alternative. Frequently, caregivers request respite care on week-ends and evenings, ask for in-home help, or need brief overnight options away from home. In response to caregivers' changing needs, providers are beginning to offer more user-friendly respite care options. For example, after assessing family needs, the Great Lakes Community Mental Health Agency in Traverse City offers vouchers to use with approved contract providers for adult day services, in-home respite, or brief overnight care in an adult foster care or nursing care facility. In a similar program, the Greater Michigan Chapter of the Alzheimer's Association – Detroit Region is piloting a small project to offer vouchers or "scholarships" to families for up to \$1500/year to purchase respite care services. As it has for the past 17 years, the Detroit Regional Chapter continues to offer respite care through its volunteer program that recruits and trains volunteers to provide supervision and companionship to persons with dementia at home. The Area Agency on Aging 1-B in Southfield is developing a volunteer respite program to train volunteers within the existing Faith-in-Action Network to supervise and assist persons needing care in their homes.

## **Promote best practices in Michigan respite care programs**

Various bills currently in the Michigan Legislature could affect how respite services are provided in Michigan. We support legislation that: Helps the state identify respite programs that address the needs of persons with dementia and their caregivers; promotes implementation of models of flexible, innovative respite care programs; and develops a method to disseminate these innovative models throughout Michigan. We support legislation that enables the Michigan Dementia Coalition to collaborate with the Michigan Department of Community Health in conducting an inventory of respite services for caregivers of persons with dementia. In addition, we recommend the development of a network of respite care agencies providing care for persons with dementia to increase communication and promote best practices among all participating respite providers.

The Michigan Dementia Coalition and Office of Services to the Aging will establish a work group to strengthen Michigan's respite services for dementia caregivers. The goals of the work group will be to: Assess the adequacy of access to respite services throughout the state; identify best practices, especially those that are responsive to the changing needs of caregivers and persons with dementia, in respite services; and promote increased use of best practices in dementia respite services and replication of model dementia respite services throughout the aging network.

## **Telephone-based interventions to increase caregiver skills**

Telephone-based contact with caregivers has long been a source of meeting caregivers' needs. The 1-800 Helplines offered through the Alzheimer's Association Chapters link callers with their local chapters and provide a valuable connection to support and resources. Support groups have also been a source of help routinely offered to family caregivers. Recent studies have documented the benefit of time-limited, psychoeducational skill-based support groups. One study showed that short-term psychoeducational interventions—here consisting of eight weeks for two hours/week, followed by two “booster” sessions at one-month intervals—with small groups of distressed caregivers can have a positive impact.<sup>31,32</sup> In this study, female caregivers of persons with dementia assigned to anger or depression management classes showed significant reduction in their levels of anger/hostility and depression as compared to controls.

Current work is demonstrating that elements of traditional face-to-face interventions can be translated successfully into a more cost-effective telephone-based format. For example, the intervention described above was redesigned as an 8-week videotape series, in which participants are coached on the telephone by mental health professionals to practice new skills.<sup>33,34</sup> When compared with traditional telephone support to caregivers, this skill-based

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<sup>31</sup> Coon DW, Thompson L, Steffen A, Sorocco K, Gallagher-Thompson D. Anger and depression management for caregivers: Psychoeducational skill training interventions for women caregivers of a relative with dementia. *Gerontologist*. (In press).

<sup>32</sup> Gallagher-Thompson D, DeVries HM. 'Coping with Frustration' classes: Development and preliminary outcomes with women who care for relatives with dementia. *Gerontologist*. 1994;34:548-552.

<sup>33</sup> Steffen AM, Mangum KRK. Distance-based skills training for depressed dementia family carers. *Clinical Psychologist (of Australia)*. 2003;7:1-10.

telephone-support intervention resulted in reduced caregiver depression and annoyance following behavior problems.

Another telephone-based intervention, “Health First: Caregivers Take Time to Stay Active,” conducted at the Michigan Alzheimer’s Disease Research Center, was designed to encourage the practice of regular physical activity among caregivers of persons with dementia. This nine-month program helps participants design their own exercise plan that takes into account caregiving-related barriers to exercise, such as difficulty leaving the home. In the first six months of a randomized, controlled trial with female spousal caregivers of persons with dementia, Health First participants reported greater improvements from baseline in total physical activity per week and self-efficacy for exercise, and a larger decrease in depressive symptoms, compared to controls.<sup>35</sup>

Based on these preliminary findings, we recommend expanding the use of telephone-based interventions that have demonstrated cost-effective, positive outcomes for caregivers of persons with dementia. The goal is to disseminate these and other telephone-based interventions to a target group of community-based service agencies: those well suited to offering this type of caregiver education and training. Funding for these projects is recommended as a strategy to increase caregiver skills and promote healthy caregiver behaviors.

### **Ongoing training to increase family caregivers’ skills in communicating with physicians**

The important role that family caregivers play in supporting persons with dementia requires them to communicate effectively with physicians. As the disease progresses and those afflicted with dementia are less able to communicate needs and desires, it is up to the caregiver to make sure that the person with dementia receives appropriate and timely medical care, adheres to the treatment plan, and takes medication as prescribed, as well as undertake any necessary safety precautions on the patient’s behalf. Family members can also alert the physician to changes in the person’s condition. Thus, it is particularly critical that caregivers develop good communication skills with physicians.

We recommend working with appropriate agencies to promote training workshops that help caregivers communicate effectively with physicians, whether it be to obtain a diagnostic evaluation, timely follow-up care, or appropriate community referrals. The expected outcome is that caregivers will report greater confidence in working with physicians. We support the caregiver training program currently being conducted by the Michigan Great Lakes Chapter of the Alzheimer’s Association, in collaboration with the Michigan Alzheimer’s Disease Research Center. We recommend extending this type of caregiver training program to agencies serving people with other dementing illnesses.

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<sup>34</sup> Steffen AM. Anger management for dementia caregivers: A preliminary study using video and telephone interventions. *Behavior Therapy*. 2000;31:281-299.

<sup>35</sup> Connell CM, Janevic MR, Hudson ML. Effects of a telephone-based exercise program for female spouse caregivers of dementia patients. Presented at the 8<sup>th</sup> International Conference on Alzheimer’s Disease and Related Disorders. Stockholm, July 2002.



## **Dementia in Primary Care**

**Goal 2: Promote a public health, disease management approach to dementia care in primary care practice that makes full use of best dementia care practices.**

### **Strategies:**

- **Equip the Michigan Primary Care Physicians Dementia Leaders Network to implement its plan by developing the network infrastructure.**

Provide staff support and the capacity to develop a website and implement the Michigan Primary Care Physicians Dementia Leaders Network plan.

- **Link and develop centers of dementia assessment, diagnosis, and clinical best practices.**

Identify current dementia assessment centers and help them network with each other to make it easier to spread best dementia care practices throughout the state.

- **Demonstrate community models of dementia best care practices.**

Set up several demonstration projects in underserved rural communities to help primary care physicians establish formal procedures for linking families to community services.

Michigan's primary care physicians are uniquely positioned to improve the quality of life of persons with dementia and their caregivers, and to reduce or delay associated health care costs. However, many physicians feel ill equipped to provide meaningful care to patients with dementia. In December 2001, the Michigan Dementia Coalition convened thirty primary care physicians seen as dementia leaders in their communities. These physicians identified barriers to providing excellent dementia care. Chief among them was this: Identifying dementia opens Pandora's box. Once dementia is identified, what is a physician to do? Participants in the December 2001 conference comprised the core of a Michigan Primary Care Physicians Dementia Leaders Network.

## The role of primary care physicians

Physicians are on the frontline in reducing the burden of dementia for families and the state. Participants in the community dementia forums clearly articulated that they expect physicians to have answers and to offer help. Early identification and ongoing management based on best practice guidelines are key to improving the quality of life of persons with dementia and their families and holding down costs.

Guidelines for best care practices in dementia consistently identify the following critical responsibilities of primary care physicians:

- **Identify memory problems in the early stages and make sure patients are accurately assessed and diagnosed.** Primary care physicians need to understand the importance of recognizing dementia and be skilled in its early detection. Failure to detect dementia early delays appropriate treatment. Unrecognized dementia leads to higher costs, due to hospitalizations for crisis behaviors or neglected general health.<sup>36</sup> Early diagnosis and treatment delays nursing home placement, limits crises, and permits advance planning.
- **Adopt an ongoing disease management approach to the care of persons with dementia.** Disease management has been defined as “a continuum of care for chronically ill patients who use or potentially will use a significant portion of health care resources over time. Disease management is an interventional relationship with a chronically ill person.”<sup>37,38</sup>
- **Monitor and treat symptoms and co-morbidities, particularly depression.** Medical treatment can stabilize or reduce cognitive decline.<sup>39</sup> Depression can be treated and eases caregiver stress while improving patients’ well-being.<sup>40</sup> Primary care physicians need to be familiar with long-term monitoring and treatment of dementia and its complications.

What a great service this would be if a person and their caregiver goes to see the doctor and the doctor knows the caregiver is having difficulty coping at home with her loved one, he could suggest to them to go to a support group meeting. That’s how I learned about support groups – through my doctor. They would be doing a great service for so many people.

Pauline Vertanen

Gwinn, Michigan  
October 28, 2002

<sup>36</sup> Shelton P, Schraeder C, Dworak D, Fraser C, Sager MA. Caregivers’ utilization of health services: results from the Medicare Alzheimer’s Disease Demonstration, Illinois site. *J Am Geriatr Soc.* 2001;49:1600-1605.

<sup>37</sup> Rubinstein HG. Disease Management: an industry grows up. *HealthLeaders Roundtable*, Sept. 2001. RMS Disease Management Inc. website at: [www.rmshealthsystems.com/pr/articles/Dereks\\_Rt\\_09\\_01.pdf](http://www.rmshealthsystems.com/pr/articles/Dereks_Rt_09_01.pdf) May 1, 2003.

<sup>38</sup> Fillit HM. Managed care decisions in Alzheimer’s disease. *Am J Manag Care.* 2000; Dec 6(22 Suppl): S1149-1155.

<sup>39</sup> U.S. Agency for Health Care Policy and Research, Early Identification of Alzheimer’s Disease and Related Dementias Panel. *Early identification of Alzheimer’s disease and related dementias, quick reference guide and clinical practice guidelines.* Rockville, MD: AHCPR, 1997.

<sup>40</sup> Moretti R, Torre P, Antonello RM, Cazzato G, Bava A. Depression and Alzheimer’s disease: Symptom or comorbidity? *Am J Alzheimers Dis Other Dem.* 2002;17:338-344.

- **Monitor and treat behavioral symptoms.** Behavioral symptoms in patients with Alzheimer’s disease significantly increase total and direct costs of care. Pharmacological treatment and psychosocial interventions for caregivers are both beneficial. Medications are often underused for behavioral symptoms that do not respond to psychosocial interventions;<sup>41</sup> treatment should target these situations. Clinicians need to be aware of the appropriate uses of pharmacological interventions and incorporate them accordingly in their treatment plans.<sup>42</sup>

- **Attend to the health of the primary caregivers.** Physicians caring for elderly individuals with dementia should be mindful of the importance of informal care for their patients, as well as the potential for significant burden on the informal caregivers, who are often elderly too.<sup>43</sup> Caregiver burden and burnout are prevalent and can be helped. Physicians aware of the signs and symptoms are in a better position to prevent it and, if it occurs, assess it and intervene before it does too much damage.<sup>44</sup>

One year before my mother died of Alzheimer’s, my dad was diagnosed with cancer. He ignored the symptoms for months because he was too busy caring for my mom and looking after his own mother as well. I am convinced Alzheimer’s caused my dad’s death as well as my mother’s.

Catherine A. Leadley

- **Work in partnership with community resources.** Persons with dementia receive optimal care when there is a strong partnership between professional and family caregivers. Family physicians have an important role in identifying caregiver problems and providing direct and ongoing support, including practical counseling about common stresses and resources to address them.<sup>45,46</sup>

Dexter  
October 11, 2002

- **Work with families to make appropriate end-stage care decisions.** Studies indicate persons with end-stage dementia receive aggressive care interventions at about the same rate as persons of the same age who do not have dementia, even though the interventions “are especially burdensome for those with dementia because they cannot understand the reasons for tests or treatments, prepare for them emotionally, refuse them if desired, or request analgesia,” and despite a lower survival rate.<sup>47</sup>

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<sup>41</sup> Murman DL, Chen Q, Powell MC, Colenda CC. The incremental costs associated with behavioral symptoms in Alzheimer’s disease. *Neurology* 2002;59:1721-1729.

<sup>42</sup> Farcnik K, Persyko MS. Assessment, measures and approaches to easing caregiver burden in Alzheimer’s disease. *Drugs Aging*. 2002;19:203-215.

<sup>43</sup> Langa KM, Chernew ME, Kabeto MU, Herzog AR, Ofstedal MB, Willis RJ, Wallace RB, Mucha LM, Straus WL, Fendrick AM. National estimates of the quantity and cost of informal caregiving for the elderly with dementia. *J Gen Intern Med*. 2001;16:770-778.

<sup>44</sup> Kasuya RT, Polgar-Bailey P, Takeuchi R. Caregiver burden and burnout. A guide for primary care physicians. *Postgrad Med*. 2000;108:119-123.

<sup>45</sup> Parks SM, Novielli KD. A practical guide to caring for caregivers. *Am Fam Physician*. 2000;62:2613-2622.

<sup>46</sup> Cohen CA. Caregivers for people with dementia. What is the family physician’s role? *Can Fam Physician*. 2000; 46:376-380.

<sup>47</sup> Morrison RS, Siu AL. Survival in end-stage dementia following acute illness. *JAMA*. 2000;284:47-52.

- **Work in partnership with allied health professionals.** Primary care physicians should counsel caregivers and family members on the need to address health care concerns that fall outside the scope of medical care, but may affect overall health during the progression of dementia. For example, there is growing evidence relating oral disease, such as untreated dental infections, to systemic disease. The associated costs are considerable in both dollars and suffering.<sup>48</sup> Treating dental pain is critical because it interferes with eating, which leads to malnutrition, and affects behavioral management as well.<sup>49</sup>

### Changing dementia care in primary care practice: what works

The difficulties inherent in changing physician practice are well known. Knowledge of best practices in dementia care is increasing rapidly and medical school training of as little as ten years ago is no longer adequate. Demands on the time of primary care physicians make it difficult for them to stay abreast of rapid advances on multiple fronts. While health care in general is moving from acute care to a chronic care orientation, dementia—perhaps more than any other chronic condition—requires this shift in approach. The needs of persons with dementia are “multidimensional, interrelated, disabling, interpersonal and on-going.”<sup>50</sup>

There are many best practice guidelines for dementia. Incorporating their essential elements into primary care physician practice requires the best educational strategies as well as system and policy changes that increase incentives to follow them. Current knowledge on changing physician practice emphasizes:

- Integrating a variety of methods<sup>51,52</sup>
- Conducting academic detailing-type visits<sup>53,54,55</sup>
- Interacting with respected peers and mentors to frame issues, brainstorm, validate and share information, make decisions, and create management protocols<sup>56</sup>

The effort to direct physicians toward adherence to accepted guidelines in their practice environment requires combined strategies and ongoing effort.  
J. E. Heffner<sup>48</sup>

<sup>48</sup> McMinn W, Merchant V, Metz W, VanHeest P. *Report of the Task Force on Access to Care for the Special Needs Patient*. Michigan Dental Association. 1999.

<sup>49</sup> Lamy M, Mojon P, Kalykakis G, Legran R, Butz-Jorgensen E. Oral status and nutrition in the institutionalized elderly. *J Dent*. 1999;27:443-448.

<sup>50</sup> Bringewatt RJ. Chronic care in the new millennium. *Geriatr Care Manag J*. 2001; 3.

<sup>51</sup> Heffner JE. Altering physician behavior to improve clinical performance. *Topics in Health Information Management*. 2001;22:1-11.

<sup>52</sup> Grol R. Changing physicians' competence and performance: Finding the balance between the individual and the organization. *J Contin Educ Health Prof*. 2002;22:244-251.

<sup>53</sup> Goldstein MG, Niaura R, Willey C, Kazura A, Rakowski W, DePue J, Park E. An academic detailing intervention to disseminate physician-delivered smoking cessation counseling: smoking cessation outcomes of the Physicians Counseling Smokers Project. *Prev Med*. 2003;36:185-196.

<sup>54</sup> Hill CD, Bunn DN, Hawkins JR. Stretching the managed care dollar in the new Millennium: the practice of detailing primary care physicians. *Manag Care Q*. 2002;10:18-23.

<sup>55</sup> Soumerai SB. Principles and uses of academic detailing to improve the management of psychiatric disorders. *Int J Psychiatry Med*. 1998;28:81-96.

- Problem-based learning<sup>57</sup>
- Built-in reminders and performance feedback<sup>58</sup>
- Highlighting and repeating essential messages<sup>59</sup>
- Case-based learning<sup>60</sup>

### **Physician network infrastructure**

The Michigan Primary Care Physicians Dementia Leaders Network affords Michigan a unique opportunity to make the changes needed in primary care practice for patients with dementia. Having reviewed dementia practice guidelines, effective models of physician dementia practice, and best practices in dissemination, the Network has drafted a plan to bring about these changes. The plan proposes wider use of electronic technology; ongoing educational updates and continuing medical education programs; “second opinion” teaching/learning clinics; development and coordination of an assessment centers network; and demonstrating best practice models at several sites around the state. The plan also advocates identifying system and policy changes to align reimbursement and other incentives with best dementia care practices, and sharing this knowledge with policymakers.

To implement this plan, the Network infrastructure needs support. Lack of staff support and an operating budget currently impede progress. Staff and an operational budget are needed to implement the full set of objectives of the Network and to make optimal use of the medical expertise that this Network offers. Objectives of the Primary Care Physicians Dementia Leaders Network and additional recommendations of the State Dementia Plan Committee are presented in Appendix D.

### **Centers of dementia assessment, diagnosis, and dementia best care practices**

One aspect of increasing early diagnosis is increasing early identification of memory problems in the primary care office. Another aspect is developing a network of dementia assessment and best practice dissemination centers. Both professional and family participants in the community forums voiced the need for more accessible dementia assessment and diagnosis centers. This need is especially apparent in the eastern Upper Peninsula and other rural areas.

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<sup>56</sup> Parboosingh JT. Physician communities of practice: where learning and practice are inseparable. *J Contin Educ Health Prof.* 2002;22(4):230-236.

<sup>57</sup> Abrahamson S, Baron J, Elstein AS, Hammond WP, Holzman GB, Marlow B, Taggart MS, Schulkin J. Continuing medical education for life: eight principles. *Acad Med.* 1999;74:1288-1294.

<sup>58</sup> Phillips LS, Branch WT, Cook CB, Doyle JP, El-Kebbi IM, Gallina DL, Miller CD, Ziemer EC, Barnes CS. Clinical inertia. *Ann Intern Med.* 2001;6;135:825-834.

<sup>59</sup> Soumerai SB, Avorn J. Principles of educational outreach (‘academic detailing’) to improve clinical decision making. *JAMA.* 1990;26;263:549-556.

<sup>60</sup> Iliffe S, Wilcock J, Austin T, Walters K, Rait G, Turner S, Bryans M, Downs M. Dementia diagnosis and management in primary care. *Dementia.* 2002;1:11-23.

The complexity of dementia assessment and diagnosis makes it difficult for many primary care physicians to offer this service. Complete assessment requires a careful and often time-consuming medical evaluation. No single or simple blood test, brain scan, or questionnaire can diagnose dementia or determine its cause. Individuals and families need to know where they can go for thorough, accurate assessment. Physicians need to know where they can refer patients with memory problems.

The Primary Care Physicians Dementia Leaders Network explored models of best practice and identified the Wisconsin Alzheimer's Institute Dementia Diagnostic Center Program as the model of choice. In 1998, the Wisconsin State legislature mandated that every citizen should be within 200 miles of a dementia specialty center, to ensure access to the highest quality dementia diagnosis and treatment. The University of Wisconsin-Madison Medical School formed the Wisconsin Alzheimer's Institute, an academic center whose mission is to improve the availability and quality of care provided to persons with dementia and their families. Its primary purpose is to help communities develop specialty services for early diagnosis and treatment as well as support for family caregivers.

Michigan's geographic and resource challenges are similar to those in Wisconsin; a statewide network could work well here too. Dementia specialty centers offering in-depth medical evaluations and the latest treatments already exist in Michigan, as do individual, group, and hospital practices providing comprehensive geriatric assessment or dementia evaluation. However, access to these services is inconsistent throughout the state and there is no system linking patients or physicians and centers. A primary goal of the Primary Care Physicians Dementia Leaders Network is to promote development of a statewide network of existing dementia centers as well as new centers to fill the gaps. University of Rochester researchers found that primary care physicians complied with most recommendations made by specialists at consultative clinics.<sup>61</sup> This statewide network can actively disseminate best dementia care practices, contributing to efforts to change primary care physician practice.

Poor management of dementia can result in a more rapid progression of disability, increased trauma for the person with dementia, and increased stress for caregivers, significantly increasing costs.

Rhonna Shatz, DO

Co-Chair  
Health Care Services  
Subcommittee, State  
Dementia Plan Committee

There is a clear need for enhancement of the role of primary care practitioners in the detection and treatment of dementia, coordination of existing diagnostic clinics, and an increase in the number of diagnostic and best practice centers. With the proposed network of assessment and diagnosis centers, many more persons with dementia in Michigan will be able to connect to community support services and receive the ongoing management of their condition that is needed to reduce the costs of health care and institutional long-term care.

### **Community models of best dementia care practices**

One of the proposed strategies of the Primary Care Physicians Dementia Leaders Network plan is demonstrating best dementia care practices that link patients, physicians, and

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<sup>61</sup> Podgorski CA, Lanning BD, Casaceli CJ, Nardi AL, Cox C. Dementia consults: Predictors of compliance by primary care physicians. *Am J Alzheimers Dis Other Demen.* 2002;17:44-50.

community resources. In their book, *Chronic Conditions: Making the Case for Ongoing Care*, the authors encourage policymakers, providers, and the public to “look at health care from a new perspective: the chronic care perspective, with a special emphasis on community caregiving models.”<sup>62</sup>

The demands of caring for persons with dementia often overwhelm caregivers. Community-based programs can help caregivers shoulder the burden. Use of these services has been shown to decrease caregiver stress and, in some cases, delay or prevent institutionalization.<sup>63</sup> Benefits are maximized when caregivers get support from community services early in the course of the disease.<sup>64</sup> Too often, however, family caregivers are not aware of the support services available to them when their relative is first diagnosed with dementia.<sup>65</sup>

The Area Agency on Aging of Western Michigan offers an example of effective community collaboration. With Title 3E money from the National Family Caregiver Support Program, the Agency helped establish the Caregiver Resource Network in Kent County. They have funded outside agencies to work together to plan services for the region. Since 2000, approximately 30 provider agencies participate in open monthly meetings to share knowledge of available services; examine gaps in service usage and plan new programs or services to meet unmet needs; develop public awareness and marketing projects; and set up collaborative educational offerings.

To demonstrate to primary care physicians in Michigan the feasibility, process, and effectiveness of community-based support, the Physician Network proposes several demonstration projects in underserved rural communities. The main goal of the projects is to help primary care physicians build formal procedures for linking families to community services.

The National Conference of State Legislatures asserts that a state’s ability to contain costs through care coordination and disease management depends on its capacity to introduce new strategies into its existing care management system.<sup>66</sup> In Michigan, the Primary Care Physicians Dementia Leaders Network will be a valuable tool in this process. We anticipate that physician education, the assessment centers network, and the community demonstration projects will lead to earlier identification of persons with dementia, higher use of existing community-based dementia services, greater caregiver confidence in managing dementia symptoms, lower caregiver stress, and increased physician satisfaction in providing dementia care.

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<sup>62</sup>Partnership for Solutions. *Chronic Conditions: Making the case for ongoing care*. Baltimore:Johns Hopkins University. 2002, p.2.

<sup>63</sup>Zarit SH, Gaugler JE, Jarrott SE. Useful services for families: research, findings and directions. *Int J Geriatr Psychiatry*. 1999;14:165-181.

<sup>64</sup>Venohr I, Fine R, Saunders V, Tenney E, Vahan V, Williams M. Improving dementia care through community linkages: A multi-site demonstration project. *Home Health Care Serv Qtr*. 2001;19:51-63.

<sup>65</sup>Fortinsky RH, Unson CG, Garcia RI. Helping family caregivers by linking primary care physicians with community-based dementia care services. *Dementia*. 2002;1:227-240.

<sup>66</sup>Ladenheim K. *Medicaid Cost Containment: A Legislator’s Took Kit*. In *Strategy 8: Managing Health Care Better*, p. 1. National Conference of State Legislatures, [www.ncsl.org](http://www.ncsl.org), May 9, 2003.

## Health Professionals and Dementia

**Goal 3: Increase the dementia competency of health care professionals.**

### Strategies:

- **Design and implement an initiative to increase dementia training in formal professional education programs.**

Establish a Michigan Dementia Coalition work group to determine which professions to address first and study best strategies for ensuring that their training programs provide adequate dementia content.

- **Include dementia-specific requirements in continuing professional education requirements.**

The Coalition work group should review continuing professional education requirements and work with professional associations and state regulatory units to improve dementia content.

### Importance of dementia competency in health professions

Dementia-capable health care requires dementia knowledge and competency across all types of health care providers. Not enough professionals demonstrate this competency—and the need for it will intensify as the population ages. Community forum participants recounted experiences in many health care settings with different types of professionals that portrayed the enormous need for increased dementia knowledge and competency. They expressed concern about inadequately trained staff in facilities that routinely offer care for persons with dementia. They also asserted that insufficient knowledge of caregiving techniques leads to inappropriate use of medication, crisis hospitalizations, early placement in long-term care facilities, and poor quality of life for persons with dementia and their caregivers.

One of our greatest concerns is training for emergency medical personnel, hospital emergency room staff, and hospital personnel concerning effective and sensitive communication techniques when interacting with persons with dementia and their families.

Chris Simons

October 11, 2002

Providers who care for persons with dementia include physicians, physician assistants, nurse practitioners, nurses, nursing assistants, certified nurse aides, speech therapists, occupational therapists, physical therapists, psychologists, pharmacists, dentists, emergency medical workers, home health aides, social workers, and case managers. While primary care physicians provide the majority of care, specialty physicians are often involved. Primary care and specialty physicians alike need training that allows them to interact effectively with dementia patients; assess their condition, their capacity for self-care, and the support network available to them; and draw up appropriate treatment plans. Every aspect of intake



and treatment can be compromised if, for example, a urologist does not recognize that a patient has early dementia and interacts with the person as with any other patient. Imagine the terror of someone with dementia when a dentist with no dementia-specific training approaches with tools in hand.

Nurses play a key role in caring for persons with dementia and their caregivers. Nursing has been a leader among professions in identifying the special health care implications of dementia; its literature offers many examples of curricula for nursing and related fields.

The role of occupational therapists in maintaining function and quality of life for persons with dementia derives from their skills in understanding function, maximizing residual strengths, defining small changes, and modifying environments. Occupational therapists have contributed to improved dementia care in a variety of ways, from group activities to developing caregiver strength and compensations.<sup>67</sup> Speech therapy, physical therapy, and other rehabilitative therapies for persons with dementia have been inadequately researched but have great potential for contributing to the maintenance of function and quality of life. Appropriate direct interventions and a functional communication approach are considered promising approaches to speech therapy for persons with dementia.<sup>68,69</sup>

### **Gaps in dementia competency training**

Medical school and residency program curricula do not currently emphasize the prevention and early recognition of dementia. Dementia-specific education should come early in medical training to dispel stereotypes that dementia is “untreatable” or “not worth investigating,” and ideally should be offered in the context of generalist training rather than limited to a few professions.

Many of the state’s 24-hour residential care facilities, hospice facilities, adult day programs, assisted living facilities, and home health agencies specifically offer dementia care, yet staff members may receive limited or no dementia-specific training. This is despite the many dementia education programs and services currently offered in Michigan and the thousands of direct care professionals who participate in them each year. At issue are both the large number of direct care professionals and the rapid turnover in these positions: at any given time, only a small percentage of these professionals have adequate dementia training.

At all levels—undergraduate, graduate, and postgraduate—health profession education lays the foundation for competency and sets the direction of future values and approaches to care. Ongoing professional development is equally important in a world where the knowledge base changes rapidly.

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<sup>67</sup> Corcoran MA, Gitlin LN. Dementia management: an occupational therapy home-based intervention for caregivers. *Am J Occup Ther.* 1992;46:801-808.

<sup>68</sup> Mahendra N. Direct interventions for improving the performance of individuals with Alzheimer’s disease. *Semin Speech Lang.* 2001;22:291-303.

<sup>69</sup> Glickstein JK, Neustadt GK. Speech-language interventions in Alzheimer’s disease. A functional communication approach. *Clin Commun Disord.* 1993;3:15-30.

## Increasing professional dementia competence: best strategies

The Michigan Dementia Coalition should convene a multi-disciplinary work group to draft a plan for improving dementia education in training programs and continuing education. The plan should draw on best practices in educational change, prioritize the professions to be addressed, and use strategies deemed most likely to succeed.

The group should first assess how well current under-graduate, graduate and post-graduate training programs develop dementia competencies for their respective professions. Training programs and curricula need to be systematically reviewed, using tools such as *The Curriculum Management & Information Tool* database, which contains curriculum information from medical schools throughout the U.S. and Canada.<sup>70</sup>

The work group will explore with appropriate stakeholders the feasibility and effectiveness of strategies for increasing dementia training. Consideration should be given to institutional, intra-institutional, and external factors, all of which play a role in making changes to curricula and programs.<sup>71,72</sup> The medical and nursing literatures provide abundant examples of ways to improve training in medical schools<sup>73,74</sup> and nursing schools.<sup>75,76</sup>

Poor care is very costly. It costs from \$5000 to \$50,000 to heal a bed sore that could be prevented with simple turning every two hours and good nutrition and hydration.

Jan Osborn

Long Term Care  
Ombudsman, Alpena  
October 29, 2002

Changing curricula is one strategy for strengthening dementia competency.<sup>77</sup> For example, training medical students in community health centers rather than hospitals may prove an effective curriculum change.<sup>78</sup> Curricula that can serve as potential models include one developed, through a Hartford Grant, by Dr. Robert R. Frank, Associate Dean of Academic and Student Programs at Wayne State Medical School; and one for the University of Michigan Medical School developed through a grant from the D. W. Reynolds Foundation by Dr. Mark A. Supiano, Professor of Medicine at the University of Michigan and Director

<sup>70</sup> Salas AA, Anderson MB, LaCourse L, Allen R, Candler CS, Cameron T, Lafferty D. CurrMIT: A tool for managing medical school curricula. *Acad Med.* 2003;78:275-279.

<sup>71</sup> Cohen J, Dannefer EF, Seidel HM, Weisman CS, Wexler P, Brown TM, Brieger GH, Margolis S, Ross LR, Kunitz SJ. Medical education change: a detailed study of six medical schools. *Med Educ.* 1994;28:350-360.

<sup>72</sup> Seddon TD. Education—the concern of the profession? Undergraduate medical education. *N Z Med J.* 1985;98:1049-1052.

<sup>73</sup> Gerrity MS, Mahaffy J. Evaluating change in medical school curricula: how did we know where we were going? *Acad Med.* 1998;73(9 Suppl):S55-59.

<sup>74</sup> Bland CJ, Starnaman S, Harris D, Henry R, Hembroff L. “No fear” curricular change: monitoring curricular change in the W. K. Kellogg Foundation’s National Initiative on Community Partnerships and Health Professions Education. *Acad Med.* 2000;75:623-633.

<sup>75</sup> McNerney PA. Recurriculating to a problem-based learning curriculum: the Wits experience. *Curationis.* 1998;21:53-56.

<sup>76</sup> Alexander JG, McDaniel GS, Baldwin MS, Money BJ. Promoting, applying, and evaluating problem-based learning in the undergraduate nursing curriculum. *Nurs Educ Perspect.* 2002;23:248-253.

<sup>77</sup> Sachdeva AK. Faculty development and support needed to integrate the learning of prevention in the curricula of medical schools. *Acad Med.* 2000;75(7 Suppl):S35-42.

<sup>78</sup> Brown JH. Medical schools in crisis. *Eval Health Prof.* 1988;11:147-171.

of the Ann Arbor Veterans Administration Healthcare System Geriatric Research Education and Clinical Center. Curriculum changes need to be pursued in collaboration with existing internal review processes, curriculum committees, administrators, and departmental review processes.<sup>79,80,81</sup>

Curriculum change alone, however, may not be adequate.<sup>82</sup> Other potential strategies for improving professional education that should be explored include:

- Structural or organizational changes.<sup>83</sup> Organizational issues and attitudes may be more important than educational methods or curriculum.<sup>84</sup>
- Integrating changes into existing curriculum.<sup>85</sup>
- Conferences or other methods of disseminating curriculum change recommendations.<sup>86</sup>
- Development of certification programs.
- Awards, such as the Ohio Psychiatric Association Foundation annual award, given to the primary care program that provides the best psychiatric training in the state.
- Working with accreditation bodies, such as the Association of American Medical Colleges, which established the Medical School Objectives Project to set forth learning objectives to guide medical school education; the Liaison Committee on Medical Education; and the Accreditation Council for Graduate Medical Education.
- Comprehensive examinations, which can drive curriculum change.<sup>87,88</sup>
- Training grants. Education of funding sources about the importance of dementia education may prove an effective strategy.
- Continuing education requirements of licensing boards. In Michigan these include: Board of Counseling, Board of Dentistry, Emergency Medical Services Personnel, Board of Medicine, Board of Nursing, Board of Nursing Home Administrators, Nurse Aides, Board of Occupational Therapists, Board of Optometry, Board of Osteopathic Medicine and Surgery, Board of Pharmacy, Board of Physical Therapy, Physicians Assistants Task Force, Board of Podiatric Medicine & Surgery, Board of Psychology, Board of Social Work.

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<sup>79</sup> Smythe CM, Butler PW, Jones AB, Wilson MP. Departmental review in medical schools: focus and functions. *J Med Educ.* 1979;54:284-293.

<sup>80</sup> Hendricson WD, Payer AF, Rogers LP, Markus JF. The medical school curriculum committee revisited. *Acad Med.* 1993;68:183-189.

<sup>81</sup> Levine HG, Brinkley BR, Bryan GT. Internal review as a means of maintaining quality education in a medical school. *J Med Educ.* 1977;52:478-483.

<sup>82</sup> Shahabudin SH, Safiah N. Managing the initial period of implementation of educational change. *Med Teach.* 1991;13:205-211.

<sup>83</sup> Burke W, Baron RB, Lemon M, Losh D, Novack A. Training generalist physicians: structural elements of the curriculum. *J Gen Intern Med.* 1994;9(4 Suppl 1):S23-30.

<sup>84</sup> Hodges B, Inch C, Silver I. Improving the psychiatric knowledge, skills, and attitudes of primary care physicians, 1950-2000: a review. *Am J Psychiatry.* 2001;158:1579-1586.

<sup>85</sup> Guze PA. Cultivating curricular reform. *Acad Med.* 1995;70:971-973.

<sup>86</sup> Berman MS. Time for educational reform. *J Am Optom Assoc.* 1992;63:775-776.

<sup>87</sup> Kappelman MM. The impact of external examinations on medical education programs and students. *J Med Educ.* 1983;58:300-308.

<sup>88</sup> Williams RG. Use of NBME and USMLE examinations to evaluate medical education programs. *Acad Med.* 1993;68:748-752.

The work group should also study the experience of other attempts to change medical education, such as in the fields of substance abuse,<sup>89</sup> nutrition education,<sup>90</sup> and family violence.<sup>91</sup> It should explore with the Department of Consumer and Industry Services the potential for on-site certificate training programs for staff members in state-regulated facilities.

Once members of the work group are familiar with existing curricula and programs and the effectiveness of approaches to improving medical training, the group needs to prioritize its goals, taking into account undergraduate, graduate, and postgraduate programs, as well as continuing education and professional development requirements of the relevant professions.

The initiative to increase dementia knowledge and competency across the spectrum of health care professionals in Michigan will lead to strategic action and ultimately change the way persons with dementia experience health care in Michigan. The end goals are the best of care, optimal health and function, and the highest possible quality of life for persons with dementia and their caregivers.

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<sup>89</sup> Fleming M, Barry K, Davis A, Kropp S, Kahn R, Rivo M. Medical education about substance abuse: changes in curriculum and faculty between 1976 and 1992. *Acad Med.* 1994;69:362-369.

<sup>90</sup> Shils ME. National Dairy Council Award for Excellence in Medical and Dental Nutrition Education Lecture, 1994: nutrition education in medical schools—the prospect before us. *Am J Clin Nutr.* 1994;60:631-638.

<sup>91</sup> Guze PA. Cultivating curricular reform. *Acad Med.* 1995;70:971-973.

## Residence Choice for Persons with Dementia

**Goal 4: Improve the choices for residence and care of persons with dementia.**

### **Strategies:**

- **Inform policymakers of the importance and benefits of enabling persons with dementia to live in the care setting of their choice.**
- **Advocate with policymakers for a long-term care reimbursement model in which care in the least restrictive environment, including one's own home, is financially viable.**

Among the primary concerns of persons with dementia and their caregivers is where the person with dementia will live. In spite of an increase in assisted living facilities and many efforts to improve long-term care options, Michigan families still find them limited and unsatisfactory. This is especially true in rural communities. Assisted living facilities and adult foster care homes in rural areas are often few and far away, and many are not dementia-friendly, despite advertising that they are. While the issues of long-term care are beyond the scope of this plan, we will support initiatives and policies that increase the choices to families for quality care.

As Michigan, along with the rest of the nation, grapples with the complex and difficult issues of long-term care, we strongly urge that the following be paramount:

- Increasing support for home- and community-based care
- Restructuring reimbursement streams to allow long-term care resources to follow the individual to the setting of choice<sup>92</sup>
- Giving persons with dementia and their families, a voice and a choice
- Increasing the home-like environment in institutional care facilities
- Increasing efforts and policies that promote quality and accountability

A least restrictive environment for people with HD seems to be more effective, especially as it relates to the behavioral and movement issues that have become somewhat problematic in the nursing home setting. Adult Foster Care homes, trained specifically to meet the complex needs of the person with HD would be a far better alternative and more cost effective method of housing those who could not remain with their families.

Charlene K. Soleau

October 11, 2002

### **A voice and a choice for the person with dementia**

A common but erroneous belief is that persons with dementia cannot participate in decision-making. Community forum participants eloquently spoke of the need to give persons with

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<sup>92</sup> The National Conference of State Legislatures recommends reconfiguring long-term care delivery systems to emphasize home and community care as a cost reduction strategy. See [www.ncsl.org/programs/health/forum/cost/strat5.htm](http://www.ncsl.org/programs/health/forum/cost/strat5.htm)

dementia more of a voice in their homes and communities. Studies have shown that many of the elderly with disabilities as well as persons with cognitive impairments can express daily preferences for care and benefit from consumer-directed programs.<sup>93</sup> Through the Michigan Department of Community Health Consumer Satisfaction Program, some members of the Michigan Dementia Coalition participated first-hand in interviews of persons with dementia about their satisfaction with in-home respite and adult day programs. Clearly, as a matter of human rights, we need to grant persons with dementia a voice and protect their power to choose to the fullest extent of their abilities.

### **Need for choices of residence and care options**

A person with dementia may live in any number of places: at home, in a group home, in subsidized senior housing, in an assisted living facility, or in a nursing home. At one time, it was common to think of various choices of residence as corresponding to a continuum of care. Mild dementia and a low level of assistance were associated with home-based care. At the other end of the continuum, advanced dementia was associated with nursing home care. Increasingly, however, the level of care that can be obtained at home, in subsidized housing, in group homes, or in assisted living facilities is expanding.

Whatever the setting, families want the place where their loved one lives to feel like home. This is sometimes known as “the least restrictive setting.” As level of care increases, it is increasingly difficult to provide a home-like setting. Because a home-like setting is important for quality of life, it is important that persons with dementia not be placed in higher care level settings than required by their stage of dementia.

Historically, nursing home care has been the only form of long-term care that Medicaid supports. This policy provided an incentive for families to place loved ones in nursing homes. Some states have obtained Medicaid waivers of this policy and are restructuring reimbursement so that long-term care dollars can be used in a variety of care settings, including home care.<sup>94</sup>

Michigan needs a long-term care program that supports persons with dementia remaining in the least restrictive environment necessary for their care. Financial incentives in long-term care need to be aligned with this goal. Guidelines are needed for each care setting that specify the medical needs best addressed in each one. The Michigan Dementia Coalition can help develop guidelines to determine the appropriate level of care needed by persons with dementia based on severity and functional abilities. These guidelines can then be used to inform placement decisions and access to long-term care resources.

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<sup>93</sup> Squillace MR, Firman J. *The Myths and Realities of Consumer-Directed Services for Older Persons*. From the Promoting Consumer Direction in Aging Services website: [www.consumerdirection.org](http://www.consumerdirection.org), April 21, 2003.

<sup>94</sup> National Conference of State Legislatures. *State Budgets' Impact on Health Care Policy: First Quarter of 2003*. State Health Policy Brief, 4(4). April 2003.

## Dementia and Public Awareness

**Goal 5: Increase early intervention by promoting public awareness of the caregiver role and the early warning signs of dementia.**

### Strategy:

- **Develop and implement a multi-phase public education campaign based on best practices in social marketing.**

The Michigan Dementia Coalition and Michigan Department of Community Health should jointly plan and implement a public awareness campaign about:

- What dementia is
- Early warning signs of diseases that may cause dementia
- Availability of resources

How much assistance to another person makes one a caregiver? Most people give help of one kind or another to other family members. The onset of caregiving is not a distinct event. Typically, spouses and family members accommodate a person's early memory losses, and this compensation increases slowly over time. The gradual increase in support is so insidious that many people are providing substantial assistance long before they begin to think of themselves as "caregivers."

Failure to recognize oneself as a caregiver is closely related to another awareness deficit in society: failure to recognize the early symptoms of diseases that cause dementia. More caregivers identifying themselves as caregivers and more people recognizing signs of abnormal aging in others are both essential if we are to reduce the burden of dementia. Early intervention hinges on awareness.

Community forum participants and all who contributed to the development of this plan identified a tremendous need for increased public awareness. Among the many key ideas and facts that the public needs to know, three are priorities: knowing what *dementia* means, recognizing the early warning signs of diseases that may cause dementia, and knowing about community resources available for caregivers.

It wasn't that long ago that a diagnosis of cancer was a closely guarded secret by family. Today Alzheimer's falls in a similar situation. We need to increase public awareness of how to recognize the symptoms and behaviors of those affected with dementia and provide supportive responses.

Bill Henderson

Gaylord  
October 29, 2002

### Knowing what dementia means

Many people have only a vague idea of what dementia is. Ask someone on the street what dementia is and a typical response is: "I think it's some kind of mental illness" or "Isn't that

like Alzheimer's?" A basic understanding of dementia is needed to help mitigate the stigma attached to it. The stigma of dementia—and Alzheimer's disease—prevents individuals and families from seeking assessment and services, prevents physicians from referring patients, increases the isolation of those affected, and contributes to the general lack of support for families and persons with dementia.

### **Recognizing early warning signs**

For early intervention to succeed, Michigan needs to identify a cohort of "gatekeepers." Gatekeeper programs are designed to equip key people in the community with the knowledge they need to identify and assist individuals in need of a specific type of help. Dementia gatekeeper programs and frail elderly gatekeeper programs target "gatekeepers" such as postal service workers, clergy, and emergency service providers to "spot" persons who may have dementia and to intervene appropriately so that needed assistance is provided.

### **Availability of community resources to assist caregivers**

The prospect of becoming a caregiver at some point is likely for most Americans, given the country's demographics. Many caregivers wait until crises occur or until they reach a breaking point before contacting voluntary health organizations for help. This may be because they do not recognize themselves as caregivers and so do not connect to information that offers assistance to "caregivers." Research in progress seeks to understand the phenomenon of caregivers identifying themselves as caregivers.<sup>95</sup> Meanwhile, to increase early intervention, it is important to help the many persons who assist those with memory loss and dementia, diagnosed or not, to learn about resources available to them. Michigan's voluntary health organizations for dementia caregivers widely promote their helplines with refrigerator magnets and distribution of helpline cards, brochures, and so forth. These awareness efforts are successful but limited by current funding. Substantially more people in the caregiving role could access available services if informed through a well-designed public awareness campaign.

To start, I believe we need a better strategy of public education in Michigan that reaches out to these families before they reach the breaking point.

Darryl Loiacano

ACSW  
LakeView Community  
Hospital, Paw Paw  
October 11, 2002

### **Increasing public awareness**

Increasing public awareness is a necessary component of any serious attempt to reduce the burden of dementia. Public awareness in partnership with media is critical: it has been cited

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<sup>95</sup> Kosloski K, Montgomery RJV. Utilization of respite services: A comparison of users, seekers, and non-seekers. *J Appl Gerontol.* (in press).



as one of the four ingredients of success in the most significant recent accomplishments in public health.<sup>96</sup>

We propose that the Michigan Department of Community Health work with the Michigan Dementia Coalition to develop a statewide dementia awareness campaign. The goals of the campaign will be to increase general public awareness of:

- What *dementia* means
- Early warning signs and the importance of accurate diagnosis and treatment
- Caregiver identity and available community resources

As has been noted, “The elusive ideal in public education campaigns is the magic bullet, where the right message is sent through the right channels to the right target with impressive results.”<sup>97</sup> Given the potential for a costly or ineffective campaign, it is essential that social marketing experts design the dementia awareness campaign with input from Michigan’s dementia experts. The Internet also provides many helpful resources that should be tapped to ensure a cost-effective campaign.<sup>98</sup> Design of the campaign will take into account:

- Social marketing strategies, including identification of target social behaviors; emphasis on positive messages; mixing media and interpersonal messages; location; and partnering with other community organizations.<sup>99</sup>
- The importance of culturally competent outreach. The higher prevalence of Alzheimer’s disease among minorities may indicate the need for increased access to and utilization of services.<sup>100,101</sup>

A well-designed, well-executed public awareness campaign will lead to broader acceptance of dementia, greater recognition of warning signs, and self-identification of caregivers. These in turn will contribute to earlier diagnosis and intervention, helping to prevent unnecessary disease complications, rapid progression of symptoms, and caregiver burnout. In this way, public awareness will help bring about the over-arching goals of improving the quality of life of persons with dementia and their families, and helping contain the costs of dementia in Michigan.

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<sup>96</sup> Isaacs SL, Schroeder SA. *Where the Public Good Prevailed*. American Prospect website, [www.prospect.org](http://www.prospect.org), December 27, 2001.

<sup>97</sup> Atkin C, Schiller L. *The impact of public service advertising*. The Henry J. Kaiser Family Foundation website, [www.kff.org](http://www.kff.org), May 9, 2003.

<sup>98</sup> See for example, [www.framesworkinstitute.org](http://www.framesworkinstitute.org) and [www.causecommunications.com](http://www.causecommunications.com).

<sup>99</sup> Patel D. *Employing social marketing strategies*. Center for Advancing Community Health website, <http://www.cachlink.org/>, May 6, 2003.

<sup>100</sup> Alzheimer’s Association. *African-Americans and Alzheimer’s Disease: The Silent Epidemic*. Chicago: Alzheimer’s Association, 2002.

<sup>101</sup> Tang MX, Stern Y, Marder K, Bell K, Gurland B, Lantigua R, Andrews H, Feng L, Tycko B, Mayeux R. The APOE-epsilon4 allele and the risk of Alzheimer’s disease among African Americans, whites, and Hispanics. *JAMA*. 1998;279:751-755.

## Appendix A: Acknowledgements

More than a hundred people participated in development of this plan. *Jan Christensen, JD, MSW*, Manager, Diabetes, Kidney and Other Chronic Diseases Section, and *Jean Chabut, MA*, Director, Chronic Disease and Injury Control Division of the Public Health Administration, Michigan Department of Community Health, urged the Michigan Coalition to develop the plan. Committee co-chairs *Judith Heidebrink, MD*, and *Peter Lichtenberg, PhD, ABPP*, guided the plan development process, participated in development of all aspects of the plan, and provided leadership for community forums. Sub-committee co-chairs, *Mike Arnold, MSW*, *Marie DiCostanza, MA*, *Sara Holmes, MPH*, *Larry Lawhorne, MD*, *Suzann Ogland-Hand, PhD*, *Rhonna Shatz, DO*, and *Ruth Smith, RN*, served as panel members for community forums and provided leadership for development of their respective sections. *Micki Horst, MA*, Dementia Coordinator, Michigan Public Health Institute, provided staff support. *Dale Adler, MA, MSW*, and *Amy Slonim, PhD*, also contributed substantially to development of the plan.

Three community forums were held to gather input from persons with dementia, families, the broad array of agencies and professionals concerned about dementia issues:

The **Southern Michigan Community Forum** was held October 11, 2002 in Lansing. *Douglas G. Chalgian*, Certified Elder Law Attorney and Board Member of the Michigan Great Lakes Chapter of the Alzheimer's Association facilitated the forum. *Beth Czyzyk*, of the Michigan Great Lakes Chapter of the Alzheimer's Association served as coordinator. Panel members were *Marie DiCostanza*, *Judith Heidebrink*, *Larry Lawhorne* and *Ruth Smith*. The following individuals gave presentations: *Glen Ackerman, MD*, *Randy Block*, *Blake Casher, MD*, *Terry Ekkens, MA, CSW*, *Danielle Elowsky, MSW*, *Richard Estes*, *Brenda Francis*, *Deena Gibson*, *Hector Gonzalez, PhD*, *Joan Harold, RN, BSN*, *Catherine Leadley*, *Darryl Loiacano, CSW*, *Carol McGowan*, *Tom McNaughton*, *Karen Mottey*, *Susan Prinzing*, *Clarisa Rojas-Bazan*, *Ken Shay, DDS, MS*, *Dave Reusser*, *Chris Simons*, *Charlene Soleau* and *Matthew Weiss, MD*.

The **Upper Peninsula Community Forum** was held October 28, 2002 in Marquette. *Patricia Cianciolo, PhD*, Associate Professor of Sociology/Social Work at Northern Michigan University facilitated the forum. *Beverly Bartlett*, Executive Director of the Upper Peninsula Regional Office of the Greater Michigan Chapter of the Alzheimer's Association coordinated the forum. *Mike Arnold*, *Sara Holmes*, *Peter Lichtenberg*, *Rhonna Shatz* served as panel members. The following individuals gave presentations: *Jacki Boxer-Silta*, *David Carl*, *Patricia Cianciolo, PhD*, *Ivan Fende*, *Bonnie Haapala*, *Kathy Herrala*, *Helen Kahn, PhD*, *Julie Kemp-Havican, BSW*, *Julianne Kirkham, MD*, *Virginia Korte*, *Marilyn Koshorek*, *Donna LaForest, RN, BSN*, *Suzanne Morris*, *Rev. Paul T. Olson*, *Shelley Ovink, ACSW*, *Millie Peters*, *Liz Peters*, *Gustav Petruske, Jr.*, *Maila Tiffany*, *Pauline Vertanen*, *Jim Wealton*, *Susan Wideman*, *JD* and *Janet Yoder, RN*.

The **Northern Michigan Community Forum** was held October 29, 2002 in Gaylord. *Christopher Hebel*, Executive Director of the Gaylord/Otsego County Chamber of

Commerce served as facilitator. *Dona Wishart*, Assistant Director of the Otsego County Commission on Aging and Public Policy Chair of the Northeastern Michigan Regional Office of the Greater Michigan Chapter of the Alzheimer's Association coordinated the forum. Panel members were *Mike Arnold, Judith Heidebrink, Sara Holmes and Peter Lichtenberg*. The following individuals gave presentations: *Susan R. Bergmann, RN, BSN, Marjorie Brandenburg, MA, Pamela Carlson, RN, Ron Dickerson, Mary Francis Dorman, Paula Gibeson, RN, BSN, Clem Goszcynski, Bill Henderson, Doug Hird, MD, Laura Kauffman, CSW, Mary J. King, RN, Bev Kuschel, Keitha Lochinski, Linda Martin, LPN, Barbra Mikowski, RNC, CNA, Suzanne Morris, Guy Moulds, Jean Peters, RN, Nancy Ragan, RN, Teri Schaffer-Nelson, ACSW, Marjorie Shepherd, Karen Slade and Chris Weaner*.

The following provided written testimony: *Kenneth L. Andree, Mark G. Bomberg, Elizabeth Jose, Terri LaCroix-Kelty, MSW, Kris Lindquist, Cindy Lindstrom, Jan Osborn, Pauline A. Popko, Patricia A. Rondeau, RN, Jane Schneider, Heddie Sumner, Valorie Troesch, and Advocates for Consumer Awareness*.

The Primary Care Physicians Dementia Leaders Network provided input at meetings on September 7 and November 16, 2002 and the following members of the Network participated in review of the plan: *Manju T. Beier, PharmD; Albert Dugan, MD; Marvin Fields, MD; Kevin T. Foley, MD; Edward Jackson, MD; and Alan N. Smiy, MD*.

Others who contributed to development of the plan include *Ellen Buist, Leslie Fried, JD, Ellen Johnson, Gloria Lanum, and Lauren Underwood*.

## Appendix B: State Dementia Plan Committee

Judith Heidebrink, MD, Co-Chair,\* Michigan Alzheimer's Disease Research Center,  
University of Michigan; Ann Arbor Veterans Affairs Healthcare Center  
Peter A. Lichtenberg, PhD, ABPP, Co-Chair,\* Institute of Gerontology, Wayne State  
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Clinical Geropsychology and Program Development for Senior Care  
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Marie DiCostanza, MA, former Education Director of the Greater Michigan Chapter of  
the Alzheimer's Association served as Co-Chair until January 2003.

Dale Adler, MA, MSW, Consultant, MDCH Mental Health and Substance Abuse Services

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## Appendix C: Community Dementia Forums

The Michigan Dementia Coalition widely publicized three community dementia forums, which were held in Lansing, Marquette and Gaylord in October 2002.

### **Southern Michigan Community Forum**

Friday, October 11, 1:00 – 4:00 p.m.

Michigan Department of Community Health, 3423 N. M. L. King. Blvd., Lansing

22 presenters

Panel Members: Marie DiCostanza, Judith Heidebrink, Larry Lawhorne, Ruth Smith

Forum Facilitator: Douglas G. Chalgian, Certified Elder Law Attorney, Board Member,  
Michigan Great Lakes Chapter of the Alzheimer's Association

Site coordinator: Beth Czyzyk, Michigan Great Lakes Chapter of the Alzheimer's  
Association

### **Upper Peninsula Community Forum**

Monday, October 28, 1:00 – 4:00 p.m.

Marquette Holiday Inn, 1951 U.S. Hwy 41 West, Marquette

23 presenters

Panel Members: Mike Arnold, Sara Holmes, Peter Lichtenberg, Rhonna Shatz

Forum Facilitator: Patricia Cianciola, PhD, Associate Professor, Sociology/Social Work  
Department, Northern Michigan University

Site Coordinator: Bev Bartlett, Executive Director, Upper Peninsula Region  
Greater Michigan Chapter of the Alzheimer's Association

### **Northern Michigan Community Forum**

Tuesday, October 29, 1:00 – 4:00 p.m.

Diocesan Pastoral Center, 611 North St., Gaylord

23 presenters

Panel Members: Mike Arnold, Judith Heidebrink, Sara Holmes, Peter Lichtenberg

Forum Facilitator: Christopher Hebel, Executive Director, Gaylord/Otsego County  
Chamber of Commerce

Site Coordinator: Dona Wishart, Assistant Director, Otsego County Commission on Aging,  
Public Policy Chair, Northeastern Michigan Regional Office, Alzheimer's  
Association

# Appendix D: Recommendations for Primary Care Physicians Dementia Leaders Network

## Education Group

### Objectives:

- Educate practicing physicians that failure to address dementia does not make the problem go away and can make patient's overall medical care more difficult
- Provide CME programs for PCPs to facilitate recognition and management of dementia
- Emphasize dementia care during residency/fellowship training of PCPs
- Inform PCPs of dementia referral centers, where patients can be evaluated when PCP does not have time/interest/expertise
- Develop and disseminate coding & billing guidelines
- Identify or develop and disseminate tools that facilitate dementia recognition, assessment and management
- Develop appropriate modules for CME programs
- Establish list-serve resource for physicians to share dementia care practices
- Incorporate current educational websites on training

### Recommendations:

1. Ensure that educational strategies and methods reflect state of the art knowledge and practice as evidenced by literature on physician education and adult education.
2. To facilitate linkage of existing resources, create a Michigan Dementia Website as an educational and informational resource for both consumers and health care providers. Include in the website:
  - General information about dementia and care issues pertinent to all types of dementia (e.g. financial and legal implications, home safety, respite, end-of-life care)
  - Information about specific dementing illnesses and links to sites of expertise for uncommon dementias
  - A geographical listing of dementia diagnostic centers, independent providers specializing in dementia, and community-based dementia services
  - Practice parameters for dementia diagnosis and treatment
  - Insurance coding guidelines for provision of dementia care
  - A listing of dementia-specific continuing education courses for health professionals
  - Links to research opportunities in dementia within Michigan
  - Links to national dementia-specific websites
  - Information about the statewide dementia telephone helpline



3. Use the Michigan Parkinson Initiative (MPI) “Second Opinion” clinics as a model for teaching/learning. The MPI, a collaboration among the Michigan Parkinson Foundation, Henry Ford Health System, Michigan State University, St. John Health System, University of Michigan, Wayne State University, and William Beaumont Hospital, organized 13 local and 2 regional multidisciplinary ‘second opinion’ clinics to provide expertise in Parkinson’s Disease to underserved areas. Importantly, local health professionals were invited to attend these clinics, thereby extending the impact of the clinics by transferring expertise to the community. Participating physicians and patients reported an overwhelmingly favorable perception of the program.

Provide hands-on educational opportunities to community physicians through either a “traveling” dementia clinic or by completing a “mini-fellowship” at an existing dementia specialty center.

4. Clinics in the assessment and diagnosis network should serve as teaching/learning centers throughout the state.

## **Community Models / Program Group**

### Objectives:

- Plan a statewide dementia screening day – possibly incorporate into locally-scheduled health fairs
- Collaborate with community agencies to develop resource kits for physicians to be delivered personally to physicians’ offices by agency representative or physician leader
- Advocate for change in reimbursement codes for dementia care via AA, AARP, Senator Stabenow
- Establish/maintain dementia referral centers as resource for PCPs
- Perhaps include an Internet site for easy access by physicians and patients
- Develop and disseminate community model project ideas kit including recommendations to:
  - Discuss and clarify roles of various community agencies
  - Explore how communication can be improved between community agencies
  - Develop model clinic/office/practice support plan

### Recommendations:

1. Adopt the Wisconsin Alzheimer’s Initiative model of networking with assessment and diagnosis centers throughout the state. The Wisconsin Alzheimer’s Initiative emphasized the development of dementia centers throughout the state, especially in rural underserved areas. The program partially supported vital, but non-reimbursable services such as social services, start-up and marketing, training to clinic personnel

at the University of Madison-Wisconsin, linkage to community resources, and systematic data collection for public policy and research purposes. The center continuously revises and upgrades all aspects of dementia care services and disseminates the information through its statewide network.

2. Advanced dementia necessitates additional health care resources, as frail and homebound patients cannot access physicians' offices or dementia specialty centers. Explore opportunities for care by home physicians for frail and homebound dementia patients and advocate for appropriate reimbursement for dementia evaluations and care.

## **Advocacy Group**

Objectives:

- Advocate dementia education reimbursement
- Advocate regional dementia education centers
- Advocate coding/billing/reimbursement changes
- Delineate incentives/reimbursement issues and recommend appropriate changes
- Share results of reimbursement code survey (See Research Group Objectives) with AGS, AMDA, CMS, MDCH and MSMS
- Advocate for financial incentives ("bonuses") from insurers for physicians who meet quality indicators in dementia care, emphasizing that early recognition will save insurance dollars in the long run

## **Research Group**

Objectives:

- Continue outcomes research into benefits of early diagnosis and treatment of dementia
- Conduct survey to determine reimbursement codes PCPs currently use for dementia evaluation
- Determine actual triggers for Medicare audits
- Demonstrate cost savings of dementia recognition

## Appendix E: Ten Warning Signs of Alzheimer's Disease

*Reprinted with permission from the Alzheimer's Association, July 2003.*

Some change in memory is normal as we grow older, but the symptoms of Alzheimer's disease are more than simple lapses in memory. People with Alzheimer's experience difficulties communicating, learning, thinking, and reasoning — problems severe enough to have an impact on an individual's work, social activities, and family life. The Alzheimer's Association believes that it is critical for people with dementia and their families to receive information, care, and support as early as possible. To help family members and health care professionals recognize warning signs of Alzheimer's disease, the Association has developed a checklist of common symptoms.

- 1. Memory loss.** One of the most common early signs of dementia is forgetting recently learned information. While it's normal to forget appointments, names, or telephone numbers, those with dementia will forget such things more often and not remember them later.
- 2. Difficulty performing familiar tasks.** People with dementia often find it hard to complete everyday tasks that are so familiar we usually do not think about how to do them. A person with Alzheimer's may not know the steps for preparing a meal, using a household appliance, or participating in a lifelong hobby.
- 3. Problems with language.** Everyone has trouble finding the right word sometimes, but a person with Alzheimer's disease often forgets simple words or substitutes unusual words, making his or her speech or writing hard to understand. If a person with Alzheimer's is unable to find his or her toothbrush, for example, the individual may ask for "that thing for my mouth."
- 4. Disorientation to time and place.** It's normal to forget the day of the week or where you're going. But people with Alzheimer's disease can become lost on their own street, forget where they are and how they got there, and not know how to get back home.
- 5. Poor or decreased judgment.** No one has perfect judgment all of the time. Those with Alzheimer's may dress without regard to the weather, wearing several shirts or blouses on a warm day or very little clothing in cold weather. Individuals with dementia often show poor judgment about money, giving away large amounts of money to telemarketers or paying for home repairs or products they don't need.
- 6. Problems with abstract thinking.** Balancing a checkbook may be hard when the task is more complicated than usual. Someone with Alzheimer's disease could forget completely what the numbers are and what needs to be done with them.

7. **Misplacing things.** Anyone can temporarily misplace a wallet or key. A person with Alzheimer's disease may put things in unusual places: an iron in the freezer or a wristwatch in the sugar bowl.
8. **Changes in mood or behavior.** Everyone can become sad or moody from time to time. Someone with Alzheimer's disease can show rapid mood swings—from calm to tears to anger—for no apparent reason.
9. **Changes in personality.** People's personalities ordinarily change somewhat with age. But a person with Alzheimer's disease can change a lot, becoming extremely confused, suspicious, fearful, or dependent on a family member.
10. **Loss of initiative.** It's normal to tire of housework, business activities, or social obligations at times. The person with Alzheimer's disease may become very passive, sitting in front of the television for hours, sleeping more than usual, or not wanting to do usual activities.

If you recognize any warning signs in yourself or a loved one, the Alzheimer's Association recommends consulting a physician. Early diagnosis of Alzheimer's disease or other disorders causing dementia is an important step in getting appropriate treatment, care, and support services.

