

MICHIGAN DEMENTIA PLAN

Reducing The Burden
Of Dementia In Michigan

SUMMARY

Michigan Dementia Coalition
Michigan Department of Community Health

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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.

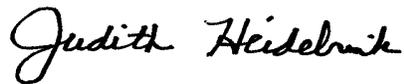
To help ensure implementation of this plan, we ask that the Michigan Department of Community Health:

- 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.

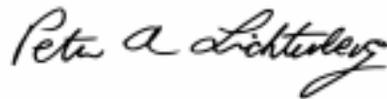
For our part, we are moving ahead even now with this plan and will continue to pursue these goals with the same collaboration and dedication that have been the hallmark of the Michigan Dementia Coalition and dementia stakeholders throughout the state.

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 Healthcare
Center



Peter A. Lichtenberg, MD
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

Table of Contents

Executive Summary	1
Stories of Remembrance	
The Daniels	6
Rose’s Letter to Her Daughter	8
Dr. Stewart Millon	9
Appendix A: Acknowledgments.....	11
Appendix B: Michigan Dementia Plan Committee	13
Appendix C: Community Dementia Forums.....	16
Appendix D: Recommendations for Primary Care Physicians Dementia Leaders Network.....	17
Appendix E: Ten Warning Signs of Alzheimer’s Disease	20
Appendix F: Michigan Dementia Helplines.....	22

Michigan Dementia Plan: Reducing the Burden of Dementia in Michigan

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 the lives of 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

*What **individuals** can do to help:*

Familiarize yourself with the early warning signs of dementia. See Appendix E.

Be alert for signs of dementia in family members and neighbors. If you see signs of dementia, help them get an assessment and diagnosis. For guidance, call the Michigan Alzheimer’s Association helpline: 1-800-337-3827

Learn some basic skills for communicating with persons with dementia and look for opportunities to practice them. Call the Michigan Alzheimer’s Association helpline at 1-800-337-3827 or see www.alz.org.

Volunteer. Be a companion to someone with dementia. Be an advocate for people with dementia. Find out ways you can help.

Promote awareness of dementia among your family, friends, and colleagues.

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

What care partners can do:

Make it a goal to *embrace* your role as care partner.

Equip yourself with knowledge about the disease, about community resources, and about giving care. Call the Michigan Alzheimer's Association helpline at 1-800-337-3827, or visit www.alz.org

Consider joining a support group. Call the helpline above for more information.

Look for and nurture your loved one's remaining capabilities.

Care for yourself.

What legislators can do:

Familiarize yourself with the costs of dementia in Michigan and the burden of dementia for families--your constituents.

Appropriate the funding needed to implement this plan.

Support legislation designed to improve the quality of life of persons with dementia and their care partners.

Support funding and regulations that permit the use of Medicaid dollars in the setting of choice.

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.

*What **physicians** can do:*

Familiarize yourself with dementia practice guidelines and consider how they can be more fully implemented in your practice. Every relevant major medical society publishes guidelines for diagnosis and treatment. Find them at <http://www.guideline.gov> or use the dementia clinical tools and guidelines of the Chronic Care Network at : <http://www.nccconline.org/about/alzheimers.htm>

Get to know the resources in your community and make sure patients with dementia or their care partners are linked up with them. Contact the Alzheimer's Association, Huntington's Disease Society of America – Michigan Chapter, and the Michigan Parkinson Foundation to find out how they can help you and your patients with dementia.

Prominently display helpline cards for patients to take. Watch for early signs and symptoms of dementia in patients 40-60 and older. If indicated, ensure accurate assessment and diagnosis.

Know the eligibility requirements for hospice for dementia patients. Encourage families to enroll as appropriate.

Watch for signs of stress and fatigue in patients who may be care partners to persons with dementia. Care partners are most likely to be elderly spouses or adult daughters, although others—including adult sons—can be too. Refer care partners to community services.

Promote awareness of dementia best care practices among your colleagues.

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.

What other health and service professionals can do:

Familiarize yourself with the signs of dementia. See Appendix E.

Be alert for these signs in patients and clients. If you see them, help get appropriate referrals to a physician or agency for follow up. For guidance, call the Michigan Alzheimer's Association helpline at 1-800-337-3827.

Prominently display helpline cards for patients to take.

Develop your skills in communicating with persons with dementia. Call the helpline number above for assistance in locating resource materials or identifying educational opportunities.

Find out if there are dementia-specific resources for your profession.

Become a leader in making your colleagues aware of dementia-specific resources and educational materials.

Give persons with dementia a voice in planning programs and services.

- 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.

What businesses and employers can do:

Learn about the ways dementia impacts businesses and employees. Get a copy of the report *Cost to Business 2002: Alzheimer's Disease Cost to American Businesses*, released by the Alzheimer's Association and the U.S. Chamber of Commerce. You can view the report at www.alz.org or contact the Michigan Alzheimer's Association helpline at 1-800-337-3827 to get a copy.

Provide opportunities for employees to learn about dementia, caregiving, and community resources available to them.

Find out if any of your employees are involved in giving care. Seek their input in designing work policies and employee benefits for your mutual benefit.

Stories of Remembrance

The Daniels



David Daniels lives in Lakeview, Michigan, with his wife Barbara, two daughters, and a son. David has been diagnosed with frontotemporal dementia, a progressive brain disorder that is often mistaken for Alzheimer's disease. Estimates suggest it represents 10% to 15% of all cases of dementia.

Several years ago, David, 44, was a line coordinator for Black and Decker in Maryland, supervising twenty-five employees. Then he began to notice that he was having short-term memory problems and trouble with routine math calculations. At first, he attributed these difficulties to stress. Two years ago, David quit his job and the Daniels moved to Lakeview, Michigan, so David could work with his brother. David thought the new job would be less stressful.

As months passed, both he and his wife noticed other changes, including personality changes. "I told Barbara I was getting aggravated," explains David. "I was starting to stutter. You think you know what you want to say but you can't say it." The Daniels shared their concerns with their family physician. He gave David a Mini Mental Status Exam; the results were not

What communities can do:

Assess the residential options for persons with dementia in your community.

Assess the dementia competence of residential facilities where persons with dementia live.

Assess support services for persons with dementia and their care partners.

Find out what other communities have done to support people with dementia and their care partners.

Promote dementia awareness in the community. Support the Alzheimer's Association, the Huntington's Disease Society, and the Michigan Parkinson Foundation in their efforts to serve persons with dementia and caregivers.

Work with the Alzheimer's Association to provide training for law enforcement officers, emergency response personnel, firefighters, postal service employees, etc. so they can respond appropriately to persons with dementia in the community.

good. He then referred David to the Mary Freebed Hospital in Grand Rapids for a psychological evaluation. Soon after, the Daniels learned that David has frontotemporal dementia.

Right now, the Daniels live one day at a time and David accepts his disease with good humor. “This is what they diagnosed me with and so I’ve got to live with it. I’ve got plans for the future, but I take it one day at a time. I take it one step at a time.”

Barbara is somewhat more practical in her outlook. She works part-time one block from the Daniels’ home and her employer understands her situation, so she can run home when needed. “We look out for our neighbors and they look out for us,” Barbara says. “The hardest part for me is trying to make the money stretch to everything the kids need. Anything we do – even going camping – we have to budget it.”

“Making the money stretch is not easy,” Barbara continues. “I just can’t make the money stretch to get the Reminyl every month. The Alzheimer’s Association has been helpful referring me to places that can help. And I go to the support group once a month. Even though they’re mostly older, we’re all going through the same thing.”

Looking ahead, Barbara thinks about what they will need and how they will manage. As for David, he says, “I’ll be grateful if we have ten more years. I’ll be *happy* if we have 20! When I think about the baby graduating and getting married . . . I can’t think about that. It makes me too sad.”

What managed care providers can do:

Familiarize yourself with the Chronic Disease Consortium approach to dementia care. Visit <http://www.nccconline.org/about/alzheimers.htm>

Review clinical practice guidelines for dementia. Every relevant major medical society publishes guidelines for diagnosis and treatment. Find them at <http://www.guideline.gov> or use the dementia clinical tools and guidelines of the Chronic Care Network: <http://www.nccconline.org/about/alzheimers.htm>

Learn about and apply dementia best practice guidelines.

Align policies, incentives and reimbursement to promote implementation of dementia best care practices.

Make sure that acute care setting staff have adequate dementia training.

Rose's Letter to Her Daughter

Rose Borgerson, 73, wrote this letter to her daughter in 1995, more than ten years after she first began having symptoms of dementia. Her husband, Oscar, cared for her at home for many years until recently, when she moved to a nursing home in Battle Creek. Oscar visits her every day and helps her with eating. "She's having trouble swallowing, but she likes to eat," he says. "She's like a little kid – she loves ice cream. You take the spoon and put a little ice cream on top of the food and she sees that ice cream and she opens right up."

Friday April 28, 1995

I think of you so often thru the day. Wonder how you are and what your doing. Please write to me and let me know how things are. I'm so lost. Oscar is such a good man. I wonder about you all the time. Let me know how you are.

I love my family, and miss you.

Please send me a note so I know what's happening.

Come see us one time. It's hard not to know what you're doing. I want to see my mom. But, I don't think she's alive anymore. Let me know if you know this. I love you all and think of you. Please write a note. I would appreciate this. Love to you all.

Rosie

Let me know about my mom. Please!

Cabbage rolls

Parboil cabbage leaves and don't do it too long cause it will get all wilted

Par Boil cabbage leves

1 onion Salt and pepper

rice

Mix together and wrap in cabbage leaves. Don't boil the cabbage too long it might get to limp (too limp)

After its cooked pick up with large spoon or whatever and cool to room temp.

Make sure you take care of Stephen.

Watch out for yourself.

Dr. Stewart Millon

Dr. Stewart Millon was a man with a smile that would light up any room. A man of great faith, he willingly provided financial, emotional, and spiritual support to his family, friends and parishioners. After a 20-year career as an attorney, he began a second career as a Lutheran minister, serving those in need for another 20 years. Once retired, he continued his service to others as a part-time chaplain in the Lutheran Care Facility. He was blessed with a loving family: a wife, daughters, grandchildren, and great-grandchildren. In all of his roles, he was a pillar of strength and a source of support to anyone in need.



When Stewart was in his mid-sixties, his wife, Elaine, began noticing a few signs that indicated a failing memory, and could sense that at times “he was not really Stewart.” Sometimes he would forget the names of parishioners he had known for years. Other times he would be unable to form complete sentences. A man who had written and delivered countless sermons, he was beginning to forget what he had written earlier in the week for his sermon on Sunday.

To find out what was wrong, Elaine scheduled a visit with Stewart’s physician, who, after examining him, suggested he enroll in a two-month course of in-depth tests at the University of California San Diego. When the tests were done, Stewart, along with his wife and two daughters, met with a panel of doctors to discuss their findings and diagnosis. This was the first time the family learned that the patriarch of their family had Alzheimer’s disease.

The definitive diagnosis of Alzheimer’s marked the beginning of this family’s journey of coming to terms and coping with the realities of this disease. Over the course of the next ten



years, the family - wife, daughters and son-in-law - formed a support system to provide a comfortable and loving environment for Stewart. Accepting the diagnosis was the hardest part for the family: “You don’t know where to start, or how to wrap your arms around the diagnosis of Alzheimer’s.” Shortly after his diagnosis, when his daughter Paula asked him to describe what it was like for him, Stewart said, “you get out of bed to get a cup of coffee and find yourself in the bathroom instead of the kitchen.”

Stewart was a stoic man, who rarely showed his feelings. As the disease progressed, he became

more aware of its effect, which produced emotions ranging from frustration to anger. He would tap his head and say, “Stupid brain won’t work,” as he struggled to communicate with his family. Early on, just after the diagnosis, the family noticed that Stewart had trouble speaking clearly and was making up words. Over time, his words and speech became complete gibberish.

Caring for Stewart began in the family home and continued for over six years, but after Elaine was admitted to the hospital with symptoms of a heart attack, the family made the heart-wrenching decision to move Stewart to a nursing home. The family spent countless hours with Stewart, providing round-the-clock care, and took every opportunity to bring him home for a few hours each week.

In late 1996, as Stewart’s life neared its end, the family moved him to his daughter’s home. His last twenty-one days were spent in her home surrounded by his loving family.



The love, attention, and constancy of care given by Stewart’s family lessened his agitation, fear, and anxiety—and made an enormous difference in the quality of his life during his final years. Those who work with Alzheimer’s patients say that there are “windows of opportunity” where “they are themselves for a while.” As a result of the love and attention bestowed, his daughter Paula believes that Stewart was able to relate with family members and stay connected much longer than he could have without it, and wasn’t as lost in his dementia. Stewart, the man with the beautiful singing voice, a lover of slapstick comedy, who opened up his heart to his family, his parishioners and his many friends, remained more within that window of his true self, rather than being closed off from his loved ones. And in the end, that made all the difference.

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, and 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*

Peter A. Lichtenberg, PhD, ABPP, Co-Chair*

Persons With Dementia and Their Caregivers Subcommittee

Sara Holmes, MPH, Co-Chair*

Education Coordinator, Michigan Alzheimer's Disease Research Center
University of Michigan

Suzann Ogland-Hand, PhD, Co-Chair*

Clinical Geropsychology and Program Development for Senior Care
Pine Rest Christian Mental Health Services, Grand Rapids

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

Lorna Alger, BA, Medical/Elders Social Worker

Nora Barkey, AAA Contract Coordinator, Grand Rapids

Louise Blasius, MSW, McKenzie Memorial Hospital, Sandusky

Beth & Don Colaner-Kenney, Michigan Parkinson Foundation

Kim DeHart, MS, Program Director, Michigan Great Lakes Chapter, Alzheimer's Association

Mike Faber, Older Learner Center, Grand Rapids

Holly Kibble, Sault Ste. Marie Tribe of Chippewa Indians

Lisa Lambert Gray, MSW, Training Coordinator, Alzheimer's Education Program, Eastern
Michigan University

Bob Lentner, President, Huntington's Disease Society of America – Michigan Chapter

Kathy Letts, Consumer Representative, Michigan Dementia Coalition

Regina McClurg, MSW, CSW, Vice President of Professional Development, Gerontology
Network, Grand Rapids

Ilene Orlanski, Respite Director, Greater Michigan Chapter of the Alzheimer's Association

Debby Orloff-Davidson, RN, Chief Executive Officer, Michigan Parkinson Foundation

Micheline Sommers, MSW, Geriatric Services Supervisor, Oakland Family Services, Rochester
Hills

Rev. Clayton L. Thomason, JD, MDiv, Assistant Professor, Spirituality & Ethics, College of
Human Medicine, Michigan State University

*Steering Committee Member

Health Care Services Subcommittee

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Department of Neurology, Henry Ford Health Center

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Glen Ackerman, MD, Michigan State University

Manju Beier, PharmD, FASCP, President, Geriatric Consultant Resources

Alan Dengiz, MD, Senior Health Services, Ann Arbor

Brenda Francis, MA, SLP, Family Services Coordinator, Huntington's Disease Society of America – Michigan Chapter

Carl Gibson, PhD, Program Director, Center for Long Term Care, Michigan Public Health Institute

Hector Gonzalez, PhD, Department of Epidemiology, University of Michigan

Bradley Jacobs, MD, MS, Wayne State University School of Medicine

Michael Maddens, MD, Director, Geriatric Medicine, Beaumont Hospital

Daniel Murman, MD, MS, Department of Neurology, Michigan State University

Michael Paletta, MD, Medical Director, Hospice of Michigan

Mark Royer, RN, ACSW, Director of Clinic Services, Masonic Pathways, Alma

Christopher Smiley, DDS, Trustee, Michigan Dental Association

Maila Tiffany, Board Member, Upper Peninsula Region, Greater Michigan Chapter of the Alzheimer's Association

Public Awareness & Public Health Subcommittee

Michael Arnold, MSW, Co-Chair*

Executive Director, North/West Michigan Chapter of the Alzheimer's Association

Larry Lawhorne, MD, Co-Chair*

Director, Geriatric Education Center of Michigan, Michigan State University

Mary Ablan, Executive Director, Area Agencies on Aging Association of Michigan

Donna Algase, PhD, School of Nursing, University of Michigan

Jan Caputo, PhD, PsyD, Michigan State University

Douglas G. Chalgian, Certified Elder Law Attorney, Michigan Great Lakes Chapter Board Member

Sara Duris, Public Policy Coordinator, Michigan Council, Alzheimer's Association

Mac Gwinn, Board Member and Chair of the Public Policy Committee, Michigan Great Lakes Chapter of the Alzheimer's Association

Ken Langa, MD, PhD, University of Michigan

Ruth Lentner, Chair, Patient/Family Services/Support Group Committee, Huntington's Disease Society of America – Michigan Chapter

*Steering Committee Member

Renee Mahler, Board Member, Greater Michigan Chapter of the Alzheimer's Association
Cheryl Shigaki, PhD, Director of Clinical Programs, Pine Rest Christian Mental Health
Services

Michelle Schultz, RN, BS, Director of Parish Nursing Services, Genesys Health Park
Erin Skene, Director of Michigan Public Policy Initiatives, Michigan Nonprofit Association
Maxine Thome, PhD, ACSW, MPH, Executive Director, National Association of Social
Workers Michigan Chapter

State Resource Personnel

Jan Christensen, JD, MSW*

Diabetes, Kidney & Other Chronic Diseases Section, Public Health
Administration, Michigan Department of Community Health

Patricia Degnan, MPA and Alyson Rush, MSW*

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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.

