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Alzheimer's & Dementia Alliance of Wisconsin advocacy update September 2011

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Federal issues

The Alzheimer's & Dementia Alliance of Wisconsin has been holding meetings with our Congressional delegation to discuss a number of Alzheimer's related issues including Medicare Part D, Alzheimer's research funding and the new National Advisory Council on Alzheimer's Research, Care and Services, which has been tasked with creating an Alzheimer's plan. Rob Gundermann, Public Policy Director, has recently met with Congressman Ribble in Appleton and Congressman Duffy in Wausau. He is very pleased with the response he has received from Wisconsin's Congressional representatives and was pleasantly surprised to find an old friend of our Executive Director serving as the District Director for Congressman Duffy! What a small world!

Eric J. Hall, The [Alzheimer's Foundation of America](http://www.alzfdn.org)'s president and chief executive officer, is one of the 12 people appointed to the National Advisory Council on Alzheimer's Research, Care and Services as established by the National Alzheimer's Project Act. The advisory council will provide:

- An initial evaluation of all federally funded efforts in Alzheimer's disease research, clinical care, and long-term services and supports and their outcomes.
- Recommendations for priority actions to expand, eliminate, coordinate or condense programs.
- Recommendations to reduce the financial impact of Alzheimer's disease on Medicare and other federally funded programs as well as on the families living with Alzheimer's disease.
- Recommendations to improve health outcomes.

George Vradenburg, co-founder and board chair of [USAgainstAlzheimer's](#), has also been appointed to the Council and is seeking “out of the box” ideas and recommendations for the content of our national plan – its goals, its priorities, and any of its elements.

We are putting together a list of items we feel are important to include in a National Alzheimer’s plan. **IF YOU HAVE ANY IDEAS YOU WOULD LIKE TO SHARE, PLEASE SEND THEM TO US AND WE WILL FORWARD THEM ON TO ERIC AND GEORGE!** You can send written comments to our office or e-mail [Rob Gundermann](#) and he’ll forward them on to Eric and George.

State issues

Coalition for prescription drug access

The Alzheimer's & Dementia Alliance has formed a coalition of disease and health groups to address issues related to prescription drug access. Prior authorization, step therapy and fail first are all barriers that prevent people from getting the medications they need and in some cases the medication that will work best. Rob Gundermann spoke with one doctor who was required to prescribe a drug he knew wouldn’t work and that the patient would have to take for six weeks before he would be able to prescribe another drug which he knew would work.

Rob has been hearing similar stories from doctors across Wisconsin about problems these issues have caused. It’s not just Alzheimer’s this affects, it’s a problem with all drugs which is especially distressing given that most people who have Alzheimer’s disease also have accompanying conditions that require medication. When a doctor prescribes Aricept or Galantamine for Alzheimer’s disease and then has to prescribe other medications for other conditions, it’s important that the doctor can choose the medication he or she believes is best. Doctors know about drug interactions and the side effects of those interactions. Doctors should be able to prescribe what they know works and won’t have adverse interactions but often times the barriers mentioned above limit their ability to do so. Issues like this need to be corrected.

Prescription Drug Forum November 3

The Alzheimer's & Dementia Alliance will be hosting a prescription drug forum on November 3 at the Hilton Hotel in downtown Madison. Starting time will be 12:00 pm for those who would like to join us for lunch and the main program will begin at 1:15. The program will run until 5:30 pm, at which time we may hold a town hall meeting with a federal representative. Cost of registration is \$50.00 and includes lunch. Registration is limited so early registration is advised. Forum informational topics are listed below:

- Experts from the pharmaceutical industry who will provide the latest information on Alzheimer’s drugs currently in the pipeline and what this new generation of medications will mean to you.
- Information regarding new regulations impacting the use of psychotropic medications.
- A session on behavior modification drugs and methods to reduce their usage.
- Information regarding important interactions between medications.
- Discussion of barrier issues preventing people from getting the medications they need.
- Information about why physicians should be the decision makers when it comes to what specific drug is prescribed.
- We also are coordinating a town hall meeting with a federal representative for the end of the forum.

For more information on the forum or to register, please call our office at 608.232.3400 or e-mail [Rob Gundermann](#).

Oral chemotherapy drugs

The Alliance is supporting a bill the Wisconsin Chapter of the American Cancer Society has requested to expand coverage of oral chemotherapy drugs. This is important for people with Alzheimer's disease because it means the patient can take the drugs in pill form in the comfort of their own home as opposed to traditional IV chemotherapy drugs which have to be administered in a hospital setting. Historically, intravenous treatments have been the predominant route for administering anticancer drug therapy. While oral therapies have been available for decades, the past 10 years has seen accelerated development pipeline are oral therapies.

While technology continues to change the nature of medical treatment for serious diseases such as cancer, health insurance plans have not always adapted to ensure patient access. A serious inequity can exist when cancer patients face significantly higher out of pocket costs simply because their treatment is dispensed orally rather than intravenously.

- Intravenous or infused cancer medications are typically covered under a health plan's medical benefit. In this situation, patients are usually required to pay an office visit co-payment and are not required to pay a separate fee for the drug. Many medical benefit designs offer some form of cap on member out of pocket costs.
- Orally administered cancer medications are generally covered under a health plan's pharmacy benefit. Traditional prescription drug programs, with fixed co-pays of \$25 or \$40 per prescription, do not impose large cost sharing. However, some plans require patients to pay a coinsurance for drugs of as much as 25%, 40% or higher, with no cap on out of pocket costs.

This bill would prohibit state regulated health plans from requiring patients to pay a higher copayment, deductible, or coinsurance for oral chemotherapy than is required for injected or intravenous chemotherapy.

Story project

The Alliance has joined with many other groups to develop a Wisconsin Healthcare Stories Project. If you would like to share a story about how Medicaid, BadgerCare or Senior Care have helped you or why one of these programs is important to you, please send it to us! We will include any stories we receive in a "story bank" and will use them as threats to these programs arise. Stories can be mailed to our office or e-mailed directly to [Rob Gundermann](#).

As some of you know, the Secretary of the Department of Health Services was granted broad authority in the recent budget bill to cut program funding. In the past, the Secretary would recommend cuts and the legislature would act on those proposals, but this is no longer the case. Legislative approval is no longer needed for the Secretary to cut programs. The Joint Finance Committee has what is called "passive review" but a majority of the committee members would have to vote to hold a hearing on any proposed cuts.

This is of course a concern to the Alliance, especially when the new Secretary has been tasked with cutting almost \$500 million from the Medicaid program. Having a story database will enable us to react more quickly when proposed cuts are put forward that could harm people with Alzheimer's or reduce vital services for people with this disease.

For those of you who are interested in speaking about your story, we are also developing a speakers bureau. Training will be provided for those interested in joining.

State Alzheimer's plan

The State of Wisconsin is facing a crisis in Alzheimer's care. While the number of people who have some type of Alzheimer's continues to climb, there is no state strategy or single document that addresses the comprehensive delivery of services to this population. A roadmap that guides policy makers, administrators and advocates by providing recommendations for reform is needed to put Wisconsin in the forefront in addressing the challenges posed by Alzheimer's disease.

Building on the work of the Helen Bader Speaker Series on Aging and Alzheimer's and their statewide network of providers and family members, the [Planning Council for Health and Human Services](#) is partnering with the [Helen Bader Foundation](#) and the state Office on Aging to gather the voices and wisdom of people across Wisconsin including providers, policy makers, academics, practitioners, and families and friends of individuals who have Alzheimer's disease. The goals of the process are to spread knowledge about Alzheimer's, help identify existing services and gaps in Alzheimer's care, and inform the State plan. Listening sessions are being held throughout Wisconsin and surveys are available for the public to express their opinions on the issues in discussion.

For a complete list of available surveys by subject area please see the link below. If you fill out any surveys please mention the Alzheimer's Alliance and tell them it's important that the state works with us in the comments part! We want to ensure that we have input throughout the entire process.

<http://www.handintheplan.org>

Targeting tax credits

The Alliance is exploring legislation to provide targeted tax credits for family caregivers for people with Alzheimer's disease. We have begun meeting with legislators to assess the level of support that may exist for this type of tax relief and will have more information in the future.

Campaign for Better Care

The Alliance has joined the "[Campaign for Better Care](#)" which is being led by the [Coalition of Wisconsin Aging Groups](#). The Alliance will work to ensure that the needs of people with Alzheimer's or other dementia are represented in this important campaign. As of today, 59 national organizations and their state affiliates, representing hundreds of thousands of Wisconsinites, have come together to form the [Wisconsin Campaign for Better Care](#) and the [Wisconsin Blue Ribbon Citizens Task Force](#) for quality health care outcomes and patient safety, which takes the essential next steps for patient centered care.

The Wisconsin Campaign will work to ensure that the needs of patients and their family caregivers are front and center in the delivery of health care. Special attention will be given to those vulnerable people and older adults with multiple health conditions so they receive comprehensive, coordinated, and patient family-centered health care they want and deserve.

Successful health care requires putting patients first and improving how their care is delivered. This is particularly important for people with multiple chronic conditions who make the heaviest use of the health

care system at the highest cost but with the poorest outcomes. While these complex patients exist in every age group, they are heavily concentrated among older adults.

The Wisconsin Campaign for Better Care and its Blue Ribbon Citizen Task Force will go beyond the statistics about chronic illness to put a human face on the issue, to mobilize and engage patients and families to advocate for the care they want and need, and to bring the voice of the consumer to the public policy discussions over how to improve health care delivery in Wisconsin. The goals of the Campaign are to:

- Make recommendations that will improve the health care system so that it delivers high quality, comprehensive, and coordinated care, especially for vulnerable older adults and people with chronic conditions.
- Change the fee for service compensation for health care providers and replace it with quality measures, patient safety and quality outcomes and prevention and wellness.
- Address the need for coordinated continuity of care by increasing the number of primary care providers who will triage people through today's complex and confusing health care system in Wisconsin.
- Advocate for greater insurance coverage for wellness and prevention health care programs.
- Build an effective and a sustainable health care consumer voice for quality health care by mobilizing consumers, health care professionals, young and older adults, their families and community leaders.

Appeals court ruling

The 2nd District Court of Appeals has issued a ruling that could have a significant impact on people with dementia. The case involved a woman named Helen, an 85 year old with Alzheimer's disease who resides in Fond du Lac County. The county sought to involuntarily commit Helen for treatment under chapter 51 of the Wisconsin State Statutes.

A Chapter 51 proceeding refers to Chapter 51 of the Wisconsin Statutes, also known as the Mental Health Act. The legislature enacted this law to assure the provision of a full range of treatment and rehabilitation services in the state for all mental disorders and developmental disabilities and for mental illness, alcoholism and drug abuse.

In most situations, law enforcement is alerted to the potential chapter 51 subject by an emergency phone call to authorities. Law enforcement is dispatched to the scene and assesses the situation. If the law enforcement officer believes that the person fits the criteria under chapter 51 and is dangerous or resistive enough to not be a proper candidate for voluntary services in the community, the law enforcement officer initiates an Emergency Detention.

The patient then must be evaluated at a local hospital. If the patient is "cleared" following the evaluation, they are sent to a local mental health facility. At the facility a licensed psychiatrist evaluates the person to determine if they meet the criteria for a continued commitment under Chapter 51 and to determine if the person needs voluntary services, a short term commitment for stabilization and treatment or the person has more intense needs and should be committed for a longer period of time. A probable cause court hearing must be held within 72 hours. The person committed has the opportunity at the hearing to contest the placement. If the court finds that the individual needs to be involuntarily committed the initial commitment period cannot exceed six months; however, it can be extended after the initial period at the recommendation of the doctor.

At any point during the proceedings, a doctor can request an order for involuntary medication and treatment for the subject. The doctor must have or attempt to have a conversation with the subject and try to explain the advantages and disadvantages of accepting medication and treatment. The doctor then makes the determination if the individual is competent or if the subject is substantially incapable of applying an understanding of the advantages, disadvantages and alternatives.

In Helen's case, a protective placement and guardianship had already been obtained under Chapter 55 of the Wisconsin State Statutes but the county sought to change that and have her committed under Chapter 51 which allows for longer term commitments.

In the decision issued by the District II Court of Appeals, the court determined that Helen was not a proper subject for detainment or treatment under Chapter 51 because Alzheimer's disease is not a qualifying mental condition under that chapter. The court found that chapter 51's definition of the term "degenerative brain disorder" is included only to specifically exclude it from the chapter's authority, whereas chapter 55's definition is used to specifically include it in the scope of authority granted under chapter 55's protective placement and services laws.

The case has been appealed to the Wisconsin Supreme Court but in the meantime the court's decision means that protective placements under chapter 51 can't be made solely upon behavior attributed to a degenerative brain disorder.

The corporation councils have told us that they will continue to use chapter 51 for placements when necessary until the Supreme Court rules. Our Dane County corporation council has explained it to us this way. *"Dementia, by its definition, is a degenerative brain disorder which causes memory loss in every case. However, in some cases it also causes psychosis, depression or other mood disorder, or hallucinations, etc., which fall within the legal definition of mental illness for commitment. So dementia is the "etiology" of the mental illness, but dementia is not the illness for commitment purposes."*

We will be following this closely and working with the relevant parties and decision makers as this issue moves forward.

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