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TESTIMONY of
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Ombudsman Program Supervisor; BOALTC
before the Special Legislative Council Committee
on Legal Interventions for Persons with
Alzheimer's Disease and Related Dementias
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Good morning, Representative Knodl and members of the committee. I am Kim Marheine, Long Term Care Ombudsman Program Supervisor for the Wisconsin Board on Aging and Long Term Care. I appear this morning to comment on behalf of the Board regarding proposed legal interventions for persons with Alzheimer's disease and related dementias.

As background, the Board operates the Wisconsin Long Term Care Ombudsman Program, a federally mandated advocacy service for residents of long term care facilities. In Wisconsin, our Ombudsmen provide advocacy services for residents as well as consultative and educational offerings for care providers and families on topics ranging from residents' rights and person-directed care, to preventing and dealing with resident abuse and neglect. High among the most frequently occurring consultations are those concerning persons with dementia who, because of challenging symptomatic behavior, are being or have been removed from their licensed long term care facilities of residence.

My personal background includes several years as the director of dementia services for a nursing home and later for a large long term care campus, followed by almost 10 years with the Alzheimer's Association of Greater WI where I worked as an educator and program director.

I want to share with you today an example of what has come to be typical ombudsman casework, illustrative of the many calls that our agency receives each month on behalf of residents with dementia who find their residency at risk. In this particular example, a resident

of a nursing home who had been diagnosed as having dementia due to several small strokes was threatened with involuntary discharge due to his behavior which included swearing at staff and making sexually-oriented comments and gestures. Because he still possessed very good speech and mobility the facility assumed that he was intentional in his words and gestures. When the man's wife attempted to share with the facility approaches that she had found helpful in caring for him she was told that the staff are professionals and that they would make their own approaches according to the behavior that they observed in that setting.

The staff's seeming insistence in using their approaches as opposed to those that had been effective for the gentleman's wife, resulted in a gradual increase in the frequency and intensity of the resident's behaviors. One morning during his routine care, when a nursing assistant reportedly used a firm tone in telling him that he was behaving inappropriately, the resident grabbed her arm and twisted it. The nursing assistant was sent for medical care which revealed a bad sprain, and the police were called and the resident escorted, in handcuffs, to the hospital. The resident was placed on the hospital's psychiatric unit, though he had no psychiatric diagnosis, until the time of his just cause hearing, when he was found to be diagnosed with a "personality disorder." He received several days of medication adjustments, and the family and nursing home were notified that he was ready to be transferred back to his nursing home.

The nursing home refused to accept him back, stating they were unable to meet his needs due to aggressive behavior, which had been absent both in his home prior to his admission, as well as for the duration of his hospitalization. The ombudsman intervened and the nursing home accepted him back.

The following morning after his return to the nursing home, again during his personal care, the resident made a sexual comment to the nursing assistant caring for him. His wife was called immediately and told to come and pick him up, as the nursing home refused to care for him any longer. The ombudsman again intervened, visiting the resident immediately, and determining that in his observed sedated state, he may have been able to make sexual comments but did not appear to pose any physical threat to staff or other residents. The ombudsman again reviewed the resident's plan of care with the home, made suggestions for consultations with the

Alzheimer's Association and a local memory loss diagnostic clinic, and was able to convince the home to rescind their action to have him removed. Further adjustments to his medications were made, the Alzheimer's Association reinforced some of the approaches recommended by the wife, and the resident's challenging behavior diminished to a point that appeared to be more comfortable for all.

A similar case involves a resident who was removed, in police custody, from 3 separate assisted living facilities and one nursing home. He had a diagnosis of "uncomplicated dementia-Alzheimer's type," and had no prior history of any aggressive behavior. He and his wife moved into the first assisted living residence together, where staff carried him back into the facility when he tried to go outside for a walk, which had been his habit at home. He became angry and kicked and struck out at the staff, causing no injury but causing the staff to reportedly feel they could not care for him. When that residence refused to take him back after a brief hospitalization to start psychotropic medications (which immediately made him more physically impaired), he went to another. The scenario repeated itself, despite his fragile physical state, 2 more times, until he was again hospitalized and diagnosed with "failure to thrive." He was refused admission by 26 different facilities across Wisconsin, and died before he was to move to a nursing home in Illinois, hundreds of miles away from his family and his home community. These events occurred within a span of just 10 months.

Since the Helen EF decision facilities express to ombudsmen a complete lack of confidence in the resources available to them when caring for persons with dementia who may have reactions to care or the environment that cause others to feel fearful or threatened, or which cause actual harm. Calls to ombudsmen have increased about residents who display reactions that can be very typical for persons with dementia, such as wandering, checking doors, saying no to care. Staff report being fearful that these behaviors that can be not only symptomatic of the disease but also reactions to the world and people around them, will advance to those that are, in their words, "violent." They fear not only harm to other residents and staff, but also regulatory sanctioning that further challenges an already strained level of reimbursement, but also the facility's credibility in the community. They fear being unable to employ staff willing to care for persons with dementia. And to the extreme, ombudsmen are increasingly at networking tables around the state where facilities are openly stating that they are fabricating

medical issues to get residents admitted to the hospital and then not accepting them back, are closing their dementia-specific units or will not accept admission of persons with dementia in the future, regardless of how uncomplicated the person's profile may appear.

These issues pre-date the Helen EF decision and are decades old, perhaps most recently notable by the case of Mr. Richard Petersen, whose daughters chronicled their efforts in the Milwaukee Journal Sentinel to obtain care for him from January to March 2010. Quoting Mr. Petersen's daughter as she detailed his admission to the Milwaukee County Behavioral Health Unit following 2 hospitalizations in as many days, "The staff at WMH had arranged for dad to be transferred to the MCMHC and was assured there would be a bed ready for him and he would be transported by ambulance. When we called MCMHC to determine dad's status, we were told where he was and went to see him. One of us went to see dad and found him in the Psychiatric Crisis Admissions Center at the MCMHC sitting in a wheelchair in the middle of the room among the homeless, mentally ill, and criminals. Dad is not mentally ill nor is he a criminal.

"He was tied in his wheelchair with a blanket. He had been transported via squad car with no jacket and no shoes in 24 degree weather and left there alone until someone had time to admit him. In our hearts, we believe dad would have sat there all night if one of us had not made the trip to check on him. At least two members of the county staff responsible for admitting people laughed at dad; this was witnessed by the daughter who found dad at the Crisis unit. It was pathetic and unbelievable! This was our dad afflicted with dementia, not someone looking for a place to sleep! We cry every time we think about this horrible treatment!"

This case, publicized in the Milwaukee Journal Sentinel, led to the development of a Challenging Behaviors Task Force under the leadership of the Southeastern Chapter of the Alzheimer's Association, and composed of stakeholders to include families, physicians, providers, community education and support resources, elderlaw attorneys and other specialists. Tom Hlavacek, one of the community members of this Legislative Council committee, can certainly speak to the full force of the project that has tried to bring new light to issues that have prevailed since some of the first formal work in this area to be done on a statewide basis occurred in the late 1980's.

In one meeting of the task force comments were reviewed from several counties in Wisconsin, highlighting the varied applications of Chapters 51 and 55 in cases involving persons with dementia. From the minutes of that meeting:

“As you can see, the norm around the State is to get a forced medication order for people who exhibit challenging behaviors. Getting a medication order is easier under Chapter 51 than under Chapter 55. Once the medication order has been given, people are typically discharged back to their nursing homes.”

It should be noted that not all persons with Alzheimer’s disease and related dementias have or will display behaviors that pose a threat of or actual harm to self or others. The Alzheimer’s Association will tell you, and my professional experience in this area bears this out, that if persons with dementia are cared for by persons, families, friends and paid caregivers, who understand the intricacies of the person and apply those to understanding the process of dementia, many persons can live a life filled with more quality than with trauma throughout the disease. This understanding is not as much about locked doors and psychotropic medications as it is about education about the disease and knowledge of the person affected. When we speak of the stigma of Alzheimer’s one of the things that people fear most is a personal loss of awareness and control that may land them in handcuffs and a police car for the first time in their lives.

In considering legislation to enable persons with Alzheimer’s disease and related dementias to receive dementia-considerate care and supports, we respectfully ask that the following be noted:

- Guardianships and protective placements should only occur where there is a need for a surrogate decision-maker over and above that provided via the durable power of attorney for health care. While they may impact the ability of the person affected to receive psychotropic medications or placement in a particular facility, they do not get at the root cause of the behavior that started the cascade of legal and medical intervention.

- The standards that define who can and will file for guardianship on behalf of a person with dementia vary from county to county. There are numerous instances across the state of persons living in facilities who appear to be vulnerable and in need of a surrogate decision-maker, and who have families lacking in the financial resources to petition the courts accordingly. Facilities and counties, understandably, are also either unwilling or unable to bear these costs, so times of crisis are further complicated by a lack of legal status that might afford the individual the best and most expedient treatment.
- We must all recognize that the administration of psychotropic medication only treats the immediate and observable symptoms of a potentially larger issue. Issues around the ability of a person or a surrogate to consent to psychotropic medication are well known and oftentimes thought to be problematic by long term care staff. They would willingly give these medications if only the person would consent. It should be also noted that there has as yet been no medication developed to specifically treat the behavioral concerns of persons with Alzheimer's disease or related dementias. The medications in use today were developed to treat the symptomatic behaviors of primarily younger persons with mental illness. Among the reasons given by persons or their surrogates for their unwillingness to give consent is the fear that the staff do not have the skills and abilities to be vigilant for and manage side effects that can be life threatening, and which have been well-publicized of late. Mandating enhanced training for staff, not just nurses but also nursing assistants and other support staff, may go a long way in building the trust that surrogates require when subjecting their loved ones to a potentially harmful treatment.
- Mandate and fund dementia-considerate training programs in all facilities that hold themselves up as being dementia-specific in order to get to the root causes of challenging behavior. Doing so may better prepare nursing homes and assisted living residences to be the best responders to persons in crisis, avoiding police custody and hospital admissions that only serve to further traumatize, and ultimately saving taxpayer dollars spent on such actions that only seem to persevere over time. There are at least two practitioners in Wisconsin who have expertise to share in this area, but building capacity can be expensive.

- Finally, please do not mandate changes to the regulations that currently support the fundamental rights of persons living in Wisconsin nursing homes and assisted living facilities. Changes that would further enable a provider to discharge a resident to the hospital and refuse to take them back only serve to further diminish the precious security of "home," as persons then are sometimes placed in facility after facility until they die. Instead, invest providers and communities with the tools they need to care: staff that are educated, dedicated and supported, residences that are truly "home," and a legal system that is responsive and consistent.

Quoting from a contributor to the Alzheimer's Association's report, "Handcuffed," released in December, 2010, "We had an older man at the hospital who was having challenging behaviors and we used the Star Method to look at the various issues. Part of this work is getting clues about the patient's personal life. We had him put on his favorite clothes and his glasses and hearing aid before we talked with him; this helped switch the paradigm. We found out from his wife that he liked polka music so we made sure this was available to him. By doing these things, we were able to get on top of his problematic behaviors and he was sent home from the hospital within a handful of days."

None of us knows if or when Alzheimer's disease or a related dementia might strike our family. The state of Wisconsin has grappled with these issues for more than 30 years, according to documents available in print. It's time to boldly state that we can and will do better for the citizens of our state that were and are the foundations of our communities before this generation also finds itself "handcuffed."

I thank you, Chairperson Knodl, and the Committee, for giving the Board on Aging and Long Term Care this opportunity to be part of this discussion. I will be happy to respond to any questions that you or the committee may have.