Testimony to Special Committee on Legal Interventions for Persons with Alzheimer's Disease and Related Dementias

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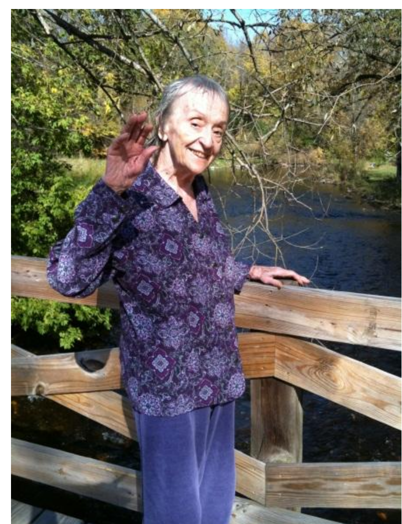
My name is Carol Wessels. I am an attorney in private practice, with my practice focused on elder law. Prior to going into private practice, I worked as the director of the SeniorLaw program at Legal Action of Wisconsin, and as a staff attorney at the Coalition of Wisconsin Aging Groups. I have been practicing elder law since 1994. I am the past chair of the Elder Law Section of the State Bar of Wisconsin, and of the Wisconsin Chapter of the National Academy of Elder Law Attorneys (WI-NAELA). I wrote the Amicus Curiae brief on behalf of those organizations in the Helen E.F. case.

My mother, Velma, has Alzheimer's. She is living in an assisted living facility called the Lighthouse in Mequon. Prior to going into assisted living, she and my father lived with me as he was in the end stages of cancer. My brother Richard and I cared for them with the help of in home care, hospice for my father, and the support of our other brothers. My mom is now in a very good facility that trains caregivers specifically to deal with challenging behaviors. I moved her from a different facility that was not caring for her appropriately.

The monthly cost of my mother's care in assisted living is over $6000. Fortunately, she and my father saved enough money for us to afford for her to be in a high quality facility. She and my father also planned ahead and signed powers of attorney for health care and other advance directives. I am Mom's health care agent. My brothers and I have spent countless hours involved in her care over the last four years. And now she does not know who we are.

Mom on her 83rd birthday in 2008.

Mom last year.



SOME FACTS ABOUT ALZHEIMER'S

Some Alzheimer's Facts: Between now and 2025 - within the next 13 years, the number of Alzheimer's patients in Wisconsin will increase by 20,000, to a total of 130,000. That is an additional 278 people with Alzheimer's in each county, if you were to divide it up evenly. Alzheimer's is currently the sixth leading cause of death, and the only one of those that does not currently have a cure. Deaths due to major medical conditions like Aids, heart disease and cancer have seen a decline due to medical advances, Alzheimer's deaths have only increased and will continue to do so. Following diagnosis, there are usually several years until death, and can be as long as 20. For my mom, it is 10 years since her diagnosis.

65% or nursing home residents in Wisconsin have some form of cognitive impairment. Between 60 and 90% of people with Dementia will exhibit behavioral issues at some point during their illness. More than 90% of nursing home patients with dementia show some form of behavioral disturbance.

I encourage you all to read the 2012 Facts and Figures report from the Alzheimer's association, http://www.alz.org/downloads/facts_figures_2012.pdf to get a full picture of the impact this disease will have on our state and country in the next several decades.

We have no choice in Wisconsin. We need proactive attention in order to maximize the quality of care for the growing number of individuals afflicted with this disease, and to create the most effective legal interventions to allow the provision of high quality care.

LEGAL ISSUES

In only a few minutes, it is difficult to detail all of the steps that need to be taken to make the legal environment for Alzheimer's patients the most effective that it can be. So I will try to hit some of the main issues that I have seen as an elder law attorney and as a family member of an individual with Alzheimer's. Following the Helen E.F. decision in the Wisconsin Supreme Court, uncertainties remain. Some counties are continuing to pursue Chapter 51 commitments of Alzheimer's patients despite the decision, arguing that on a case by case basis, a particular individual's condition can be "rehabilitated." There is a great need to provide legislative clarity with respect to the proper treatment of individuals with Alzheimer's and dementia.

First, we need to maximize the opportunity for individuals to receive needed care and treatment without court intervention. The best tool to do this is the Health Care Power of Attorney.

HEALTH CARE POWER OF ATTORNEY

1. W**isconsin's Power of Attorney for Health Care Statute prohibits admission to any inpatient psychiatric facility:** Consider an individual with Alzheimer's who has executed a health care power of attorney under Chapter 155, Wis. Stats. If such an individual did need to be admitted to a psychiatric or gerosychiatric unit in a hospital as part of a complete medical evaluation to determine the cause and treatment of challenging behaviors such as psychosis, depression or aggression, the law prevents an agent under a durable power of attorney from consenting to this admission on a voluntary basis. Wis. Stats. § 155.20(2) specifically prevents an agent from consenting to an inpatient admission to a public or private treatment facility.

155.20(2) (a) A health care agent may not consent to admission of the principal on an inpatient basis to any of the following:

1. An institution for mental diseases, as defined in s. 49.43(6m).
2. An intermediate care facility for persons with mental retardation, as defined in s. 46.278 (1m) (am).
3. A state treatment facility, as defined in s. 51.01 (15).
4. A treatment facility, as defined in s. 51.01 (19).

(b) A principal may be admitted or committed on an inpatient basis to a facility specified in par. (a) 1. to 4. only under the applicable requirements of ch. 51 or 55.

This statute makes it impossible for an agent to consent to admission that might provide useful evaluation of an Alzheimer's patient's behaviors, and forces the agent to use a much more traumatic protective placement process or mental commitment in order to obtain treatment.

The same statute also creates a problem for individuals with mental illness who wish to give their agents the ability to admit them for treatment if necessary. Many individuals with mental illness are capable of making decisions regarding their health care, including the execution of a power of attorney for health care, when their mental illness is managed. One of these decisions might be to allow their agent of choice the ability to admit them for treatment of their mental illness. However, such an admission is prohibited under Wis. Stat. § 155.20(2). Without the ability to admit a patient with mental illness for a stabilization period or medication adjustment, the agent is forced to wait until the individual's condition deteriorates to the point of dangerousness, justifying a Chapter 51 intervention.

It can be said that this prohibition was put in for good reason, namely, to prevent unnecessary admissions for persons with mental illness. But in my opinion, it goes too far. It prevents competent, intelligent individuals who happen to be mentally ill, from giving their agent the authority to obtain needed treatment.

2. **Wisconsin's Power of Attorney for Health Care Statute prohibits admission to CBRFs and skilled nursing facilities for <u>any</u> person with mental illness:** Now, consider what might happen if counties continue to pursue mental commitments for Alzheimer's patients on a case by case basis arguing that the particular individual in question can be "rehabilitated", or attempt to have people committed as "dual diagnosis" individuals in order to facilitate the continuation of the practice of Chapter 51 commitments for problematic Alzheimer's patients. Should this be the case, those individuals who had the foresight to execute a Power of Attorney for Health Care that allowed their agents to admit them to a long term care facility for purposes other than short-term rehabilitation, will find that their agents may no longer exercise that authority due to the limiting language of Wis. Stat. §155.20(2)(c). Under this statute:

> 2. A health care agent may consent to the admission of a principal to the following facilities, under the following conditions:
> c. To a nursing home or a community−based residential facility, for purposes other than those specified in subd. 2. a. and b., if the power of attorney for health care instrument specifically so authorizes <u>*and if the principal is not diagnosed as developmentally*</u>

<u>disabled or as having a mental illness at the time of the proposed admission.</u>

This limitation means that ***any individual with a diagnosis of mental illness must undergo a guardianship and protective placement proceeding in order to be admitted to a nursing facility*** or community based residential facility for long term care, even if the mental illness is not the principal reason for admission or even a significant factor. While I am fairly certain that this restriction is overlooked quite often, I can say with certainty that it is enforced in some cases, since I was appointed as <u>guardian ad litem</u> for several patients in a skilled nursing facility that was closing. Each of those patients had executed a valid power of attorney that allowed nursing home admission, but due to the above statute, they had to go through a guardianship and protective placement proceeding because state regulatory authorities overseeing the closing would not allow the agents to consent to voluntary admission due to a diagnosis of mental illness somewhere in the patients' medical records.

My opinion is that the above statutes, which limit the principal's right to delegate certain kinds of authority to an agent based solely upon the existence of a diagnosis of mental illness or developmental disability, discriminate against individuals on the basis of disability, in violation of Title II of the Americans with Disabilities Act of 1990 ("ADA"), 42 U.S.C. § 12131 *et seq.*, and Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794, in violation of the Americans with Disabilities Act, *see* <u>Hargrave v. Vermont</u>, 340 F.3d 27 (2nd Cir. 2003) (holding a state statute, which abrogated durable powers of attorney for health care executed by patients who had been civilly committed, violated the ADA and the Rehabilitation Act of 1973 by discriminating on the basis of mental illness).

3. **Power of Attorney Solutions:** A solution for both problems would be to allow a principal to choose to delegate this authority specifically, in a fashion similar to the specific delegation required for long term nursing home admission. Here is a sample:

Expanding Mental Health Treatment Authority
Limitations / Allowance on Mental Health Treatment

My health care agent **may admit or commit** me on an inpatient basis to an institution for mental diseases, an intermediate care facility for the mentally retarded, a state treatment facility or a treatment facility. This authority exists even if I am objecting to admission. ***<u>This paragraph, and not anything I may say at any subsequent time, shall constitute my desires under Wis. Stats. §§155.05(4) and 155.20(5).</u>*** I want to give my agent this authority to avoid court proceedings that could otherwise be necessary. I am aware that there is a likelihood I will object to treatment when I need it, because of the nature of my illness. I direct my physicians to abide by the decision of my agent if this document has been activated. [Principal initial here] ___________________ .

My health care agent **may consent** to the administration of psychotropic medications without the need for a court order. This authority exists even if I am objecting to medication. ***<u>This paragraph, and not anything I may say at any subsequent time, shall constitute my desires under Wis. Stats. §§155.05(4) and 155.20(5).</u>*** I want to give my agent this authority to avoid court proceedings that could otherwise be necessary. I am aware that there is a likelihood I will object to treatment and medication when I need it, because of the nature of my illness. I direct my

physicians to abide by the decision of my agent if this document has been activated. [Principal initial here] __________________.

ADMISSION TO NURSING HOMES,
COMMUNITY BASED RESIDENTIAL FACILITIES OR OTHER FACILITIES

If I have answered "Yes" to the following, my health care agent may admit me for a purpose other than recuperative care or respite care

1. A nursing home: Yes No
2. A community based residential facility: Yes No
3. Other residential facility such as assisted living, supervised apartment, etc: Yes No
4. I want my agent to be able to admit me to the above listed facilities I have selected, even if I have been diagnosed with a mental illness. Yes No

If I have not answered either "Yes" or "No" immediately above, my health care agent may only admit me for short-term stays for recuperative care or respite care.

"Refusal" paragraph: I would also recommend similar *optional* paragraphs that individuals in the early stages of dementia could elect to include that reflect a future loss of awareness regarding their condition, limitations and needs. These paragraphs would reflect that an individual in the later stages of dementia or Alzheimer's may not recognize the need for an increased level of care, and might express refusal without understanding their own needs. There are a variety of ways to word this, but one sample is:

My capacity to make directions to my agent: I understand that my agent must follow my specific directions at all times. However, I understand that, due to the nature of my disease, the time may come where I do not fully comprehend my needs and limitations. Therefore, if in the opinion of a physician or psychiatrist I lack the capacity to provide meaningful direction to my agent, my expressed opinion shall be merely informative, and shall not be considered a direction to my agent nor shall it be considered a refusal or objection to any proposed treatment or placement that my agent consents to. My expression of disagreement with my agent shall not be considered a revocation of this document.

Principal initial here: ______________

MENTAL COMMITMENTS

Plain and simple, mental commitments for Alzheimer's patients must be avoided. Here are some of the reasons:

1. Challenging behaviors are communication related. Properly trained staff can often avoid these behaviors and when they escalate to violence, the staff have not handled the situation properly. These behaviors also do not arise overnight, and should not therefore be treated with a drastic solution. At my mother's facility, when a disruptive behavior occurs, staff are given an inservice on how to approach that specific behavior. With time and proper handling, most disruptive behaviors can be addressed without the severe trauma and disruption of a mental commitment.

2. The Mental Commitment process in Chapter 51 has no place for family members or agents. Because it is set up as a psychiatric treatment law, significant protections are in place with respect to confidentiality, so that even a health care agent will not be allowed to participate in or receive information regarding the proceedings. If my mom were committed under Chapter 51, I as her agent would not know it had happened until it was over.

3. Similarly, the mental commitment process in Chapter 51 is entirely court controlled. Police remove the patient from their facility, detain the patient, and then in a confidential proceeding, a court decides whether to detain the person further, and where that person will be detained for treatment, and a court orders medication. When a health care agent is excluded from the process and the Court makes all the decisions, not only is it contrary to the advance directive of the individual, but critical information could be overlooked, such as medical history, religious preferences or other issues.

4. Treat in place must be the treatment of choice for individuals with dementia. Moving a person with dementia causes disorientation, confusion, is frightening, and traumatic. Even when I was certain my mother was going to a better facility, the trauma of transferring her was a significant consideration and she did have a period where it was difficult to orient herself. And our transfer was without police officers, handcuffs, and a locked detention cell. Mobile crisis units would be an effective and cost efficient way to treat individuals in place.

5. Where an individual must receive treatment outside the facility to address disruptive behavior, a protective placement proceeding provide considerably more involvement of family, the health care agent or guardian, and places checks and balances through a Guardian ad litem who reports to the court.

For all of these reasons and many more, I recommend that Wisconsin's Mental Commitment Law be clarified as follows:

1. to include the following bolded statement in Chapter 51.01 (13) (b),
   (b) "Mental illness", for purposes of involuntary commitment,

   means a substantial disorder of thought, mood, perception, orientation, or memory which grossly impairs judgment, behavior, capacity to recognize reality, or ability to meet the ordinary demands of life, but does not include alcoholism ***or degenerative brain disease*****.**

2. to provide a definition of "dual diagnosis" that states:

   > "Dual Diagnosis" means a diagnosis of degenerative brain disease or alcoholism, plus a diagnosis of a separately occurring mental illness that is not related to, a result of, or a symptom of alcoholism or dementia.

3. to require notice to power of attorney for health care agents or guardians and allow them to attend and participate in the commitment hearing;

Thank you for the opportunity to provide this testimony. I would be happy to consult further with the committee on these or any other issues related to the committee's charge.