

Nevada Task Force on Alzheimer's Disease

(New Proposed Recommendation)

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Proposed title for recommendation area: Choice in Care and Care Setting

Justification:

Increasingly, locked and segregated dementia care is being challenged as a potential violation of a person's human rights and civil liberties. Locked and segregated dementia care, a form of environmental restraint, includes special care units in skilled nursing facilities and assisted living communities, locked residential facilities for groups, as well as stand-alone memory care communities licensed at the assisted living level. People living with dementia have the right to choose their own living environments and remain free of forced placement.

It is important to note that holding a power of attorney over someone does not grant the legal authority to place an adult in a locked environment, even if that adult has a medically-confirmed dementia-related diagnosis. There is no legal authority for physicians to confine residents in long-term care facilities, other than in the case of specified mental health holds. Similarly, there is no legal authority giving long-term care providers the ability to hold a resident against their will. By law, there are only two people with the authority to consent to an individual's placement in a locked dementia care setting – the individual themselves or a court-appointed guardian.

Unfortunately, unjustly, and perhaps unwittingly, under this standard, long-term care facilities across Nevada may be committing false imprisonment if they do not have the documented legal consent to confine a resident (or residents) behind locked doors.

While the right to move freely is well-established under general legal principles, there are also Federal and State laws (e.g., Code of Federal

Regulations and Nevada Revised Statutes) specific to long-term care facilities that enhance the general rules, including the right to:

- Self-determination (42 C.F.R. §483.10 and 483.15(b))
- Be free from interference in exercising their rights (42 C.F.R. §483.10(a)(2))
- The right to refuse treatment to the extent permitted by law and to be informed of the consequences of that refusal (NRS 449A.112(b) and 42 C.F.R. §483.10(b)(4))
- Be free from restraint (NRS 449A.221 and 42 C.F.R. §483.13)
 - Note: In Nevada, environmental restraints are not defined in the NRS. However, according to NRS 449A.221, “mechanical restraint” is defined as the use of devices... to limit a person’s movement or hold a person immobile. In this sense, a locked door may be considered a mechanical restraint that limits a person’s movement.
- Free choice in determining treatment (42 C.F.R. 483.10(d))
- Considerate and respectful care (NRS 449A.112(a) and 42 C.F.R. 483.15(a))

Furthermore, people living with dementia, like all Nevadans, have the right to live and receive care and support in the least restrictive environment. The United States Supreme Court 1999 *Olmstead vs. L.C.* decision reinforced the right of people with cognitive impairment to live in an integrated setting for as long as they may safely do so with the necessary supports. Supporting the integration mandate in the Americans with Disabilities Act (ADA; 1990), the *Olmstead* decision asserts that the medically unjustifiable institutionalization of persons with disabilities constitutes a violation of the ADA. States must provide services to people living with disabilities, including dementia, in the community, as opposed to in an institution, to the greatest practicable extent. Failure to do so constitutes discrimination.

In addition to locked doors, there are a number of other ways long-term care facilities may attempt to confine residents living with (and without) dementia: placing alarms on doors; “redirecting” residents to stay inside when they attempt to leave; telling residents they “cannot leave” or that a “doctor has not signed off on a pass;” or by failing to providing physical assistance to residents who say they “want to leave” but are physically unable to do so.

All adults have the right to move freely and choose where they want to live and whether or not to receive health care or care services from somebody... When someone goes to a long-term care facility, they do not leave their rights at the door. They have every right not to be imprisoned, even if someone like a doctor, [family member] or a

facility administrator believes the resident does not have the capacity to make sound decisions... ***Only a judge has the ability to declare someone incompetent and take away their right to come and go as they please.*** Any other opinion regarding a person's capacity to make decisions is just that – an opinion – and has no direct legal bearing on that person's rights... The U.S. Constitution provides a right of privacy and guarantee that liberty interests may not be deprived without due process of law. The right to choose your own residence, be free from detention, and control health care decisions are guaranteed as part of the fundamental concept of liberty that Americans celebrate and defend. (California Advocates for Nursing Home Reform, 2015).

Proposed Recommendation:

The State of Nevada must ensure inclusive communities for people of *all* abilities, and uphold the rights of people living with dementia to have a say in the decisions that affect their lives, including all care decisions and choice of care setting. To protect these rights, TFAD encourages the Nevada State Long-Term Care Ombudsman's office to raise awareness across Nevada, and especially within long-term care facilities, of the definition of and issues regarding false imprisonment in long-term care. TFAD further encourages the Ombudsman's office to work collaboratively with all residents, including residents living with dementia, who do not consent to long-term care placement, and help them explore other options and alternatives, ensuring each individual's right to live in the least restrictive environment.

In addition, it is the responsibility of Nevada's Bureau of Health Care Quality and Compliance (HCQC) to ensure legal and regulatory compliance regarding the requirement for consent to placement, ensuring that no individual is confined against their will, unless authorized by a court-appointed guardian, and that each individual's preferences for care and care setting are clearly documented and honored.

Indicators:

- Clear messaging disseminated by the Nevada State Long-Term Care Ombudsman's Office and Bureau of Health Care Quality and Compliance (HCQC) outlining the legal rights of people living with dementia to choose their living environment and be free from unlawful confinement/false imprisonment.

- Proactive advocacy by Ombudsman on behalf of long-term care residents living with dementia to facilitate decision making regarding their care setting/living environment.
- HCQC brings visibility to the clear legal standards protecting choice in care setting/living environment and holds long-term care organizations accountable for compliance.

Potential Funding:

- Established operating budgets within the Ombudsman's Office and HCQC.

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