

Testimony for Public Hearing
Kansas Senate Public Health and Welfare Committee
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Michelle Niedens, L.S.C.S.W.
Alzheimer's Association, Heart of America Chapter

HB 2232 – Supporting the right for individuals to utilize electronic monitoring in long term care room.

There are many losses in Alzheimer's disease. It attacks short term memory early on, devastating it over the course of the disease. Long term memory eventually is also damaged. By middle stage, it attacks executive functions including logic, reasoning and ability to sort through step by step processes. There are also losses in the area of the brain that controls inhibition, leaving people without the vital filter between thoughts and action. Neuropsychiatric complications are common including depression, which manifests in this population primarily as anxiety and agitation. Individuals can experience delusions and hallucinations. Sleep cycle is implicated, speech is impaired and eventually lost, and in severe state, even physical ability destructed. With memory, speech and processing all interrupted, the disease renders people among the most vulnerable.

In my 30+ years working with individuals and families experiencing a dementia, I have often been witness to the pain and distress that accompanies the decision to place a loved one in a long term care facility. It is a complicated decision, and often comes with a sense that there is no other choice. The choice of a specific facility may be based on presenting symptoms, availability of bed, funding source, geography and level of care needed. All of these variables can limit, sometimes severely, the choices.

Kansas HB 2232 would allow residents of long term care facilities or their designated representatives to install electronic monitoring equipment in their personal room if they so choose. This bill supports the right of individuals regardless of age or disability to install and maintain this technology. Privacy would be respected by ensuring consent from roommates obtained prior to installation, notification to facility administrators prior to installation, appropriate notification at building entrances, visitor sign in sheets, and employee orientation.

The potential impetus for a designated representative, typically family member, to place a camera is varied and may include attempt to secure improved sense of security regarding care provision, increased understanding of a physical or behavioral challenge, or simply a desire to increase connection. With widely known staff turnover rates and inconsistent dementia training, family trust of facilities much be earned. Family caregivers simply want good care for their loved one. Use of cameras can serve to improve care. The electronic monitoring devices in individual rooms can become a possible conduit to understand difficult behaviors in dementia, understand physical health and injury of residents, and could be used to guide and advance staff training. The value of electronic monitoring is not to catch wrong doing; it is to prevent it from happening. As with all other electronic monitoring, the focus is in prevention and safety.

Medicare lists the rights of a resident as including “The right to privacy, and to keep and use your personal belongings and property as long as it doesn't interfere with the rights, health, or safety of others.” Electronic monitoring equipment constitutes the use and possession of personal belongings. It does not interfere with the rights of others as the Bill has provisions regarding roommate consent and devices would only record the specific area of the resident and not common areas. The ACLU has reviewed and submitted written testimony indicating they see no privacy violation in this bill. Additionally, many long term care facilities are already using electronic monitoring. A 2016 survey conducted by the Alzheimer’s Association Heart of America Chapter revealed that 62.5% of 104 responding long term care Kansas facilities already use electronic monitoring equipment. Six of those facilities reported that they do have cameras in resident rooms. Of the facilities with electronic monitoring equipment installed, 24.6% report that they do not inform residents, staff, or visitors in any way about the cameras and only 29% had signage on the entrance to the facility disclosing the monitoring. In order to protect the rights of all, the notification requirements of this bill exceed what is currently in practice.

We ask that you support the right of individuals to maintain some control of personal space and vote to pass HB 2232.

