

Balancing Privacy & Protection: Electronic Monitoring & Recording Devices

State of Wisconsin Board on Aging and Long Term Care
Becky Mulhern, Ombudsman Services Supervisor
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It is the philosophy of the Ombudsman Program of the Board on Aging and Long Term Care that all clients, including those with activated powers of attorney and/or guardians, have the right to participate, to whatever extent they may be capable, in all decisions impacting their choices, care, safety and well-being.

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Rights of Residents

Residents living in long-term care settings have the same rights as persons living in any community, plus additional protections related to their status as living in a long-term care setting.

These rights relate particularly to freedoms from abuse, neglect and exploitation, and the entitlement to quality, individualized care and treatment.



Electronic Monitoring and Recording Devices & Resident Rights

State and federal laws offer residents of long-term care settings specific rights to privacy in managing a resident's property, health care, and living arrangements, including relationships.

- Privacy in receiving care, medical service, counseling
- Privacy in receiving and sending mail, including email, text messages and other electronic communications
- Privacy in visits, phone calls and communications with others, including when in groups such as a resident council meeting
- Privacy to speak with an advocate, regulator, physician, or any other individual who
 may assist with resolving concerns, arranging for legal, financial or medical services

State Laws/Guidelines Regarding Privacy Rights & Electronic Monitoring and Recording Devices

- Media reports have portrayed instances where abuse has been captured on a camera or electronic monitoring device, leading some states to propose rules for how such devices are managed in long-term care settings.
- As of 2020, Illinois, Kansas, Louisiana, Minnesota, Missouri, New Mexico,
 Oklahoma, Texas, and Washington have laws that permit the installation of cameras in residents' rooms, if the resident and roommate have consented.*
- Other states, such as Maryland, have issued "guidelines" to direct the conversation around device use, consent and accountability.*



State Law Components*

- Written notices to various entities (survey agency, primarily) by the nursing home.
- Cannot involuntarily discharge or decline to admit based on device use.
- Require posting of device use in surrounding areas, resident bedroom doors.
- Law includes description of tampering with devices as being a criminal act.
- Inability to alter or intercept any image or recording without resident consent.
- Recordings admissible as evidence in criminal or civil proceedings.



Source: Oklahoma Nursing Home Care Act

State Law Resident & Decision-Maker Powers & Limitations*

- Requires written consent from both the resident and roommate before installing the device.
 - Roommate can designate limitations
 - Roommate can deny use, and resident requesting the device may be offered a room change
- Requires written notice to the nursing home of the use of the device before installing.
- Installer assumes responsibility for all costs and liabilities.
- Posting of device use on the resident's bedroom door.



Why Are Electronic Monitoring Devices Used?

From a resident's perspective:

- "Alexa" often provides music, news, weather, even a joke at a touch or voice command
- Listening devices can offer a desired immediate (virtual) connection to family or friends
- May provide some sense of security, "a quicker response than a call light"
- Some devices might turn lights or TVs on/off, make a call that residents might otherwise wait for a staff to assist with



Why Are Electronic Monitoring Devices Used?

From a family member's or other's perspective:

- Lack of trust in caregivers or systems due to past negative experience
- Prior use in other ways (able to watch kids, pets in home or day care settings)
- Intention to provide direction to the resident remotely (time for meds or bed)
- Alert if the resident gets out of bed or exits a room
- Perceived proof of allegations of abuse, neglect or theft
- Control
- Intentional identity theft, abuse or exploitation
- Peace of mind, day to day connection



Initial Findings from Oklahoma

- Deterrence of incidents of abuse, irrefutable evidence for law enforcement
- Findings of obstruction against some nursing homes
- Residents report feelings of safety and security, feeling empowered
- Residents also report concerns about personal privacy, concerns with disagreements/retaliation with/from staff and family members of differing views
- For residents with dementia, some increased challenges described as paranoia, exacerbated auditory hallucinations
- "Statistically the numbers of substantiated abuse and neglect remain relatively unchanged."



Electronic Monitoring Devices – Potential Resident Impacts

Risks and benefits of audio and video devices are dependent upon perspective:

- Security, social and community connection, immediate virtual access to family & friends
- Potential invasion of privacy when unable to consent
- Can impact privacy in intimacy (personal care, emotions, intimate or personal relationships)
- Possible vehicle for abuse when used to observe personal care, sexual expression
- Perceived loss of privacy and personal control over the most intimate moments and care
- Lack of acknowledgement for former preferences about being filmed, having images shared in ways the resident does not control
- Potential for increased disorientation, dis-ease with "random voices" with no presence of a person, especially for those with a diagnosis of dementia or mental health concerns



Electronic Monitoring Devices – Potential Staff Impacts

- Depending on approach and reason for use, could lead to strained relationships between residents, decision-makers and staff. CNAs report feeling as though they're not trusted.
- Staff report feeling that their privacy is also at risk.
- Some report feeling more prone to make mistakes due to feeling as though they're being watched.
- CNAs or resident assistants report feeling a lack of support by supervisors or the home's leadership staff.



Electronic Monitoring Devices – Use With Caution & Permission

Questions to ask and things to remember:

- O What does the resident want?
- "Nothing about me without me." Please don't leave the resident out of the discussion or the decision and be mindful to avoid undue influence.
- NEVERS: never in a bathroom, never aimed at an unclothed resident, never during personal care, never when a resident says no, and other "nevers" determined by the resident.



Electronic Monitoring Devices – Use With Caution & Permission

More questions to ask, and things to remember:

- o If used without the resident's input or consent, terms of use must be defined: time and place-limited, frequently evaluated from the resident's point of view.
- Know who will have access to tapes, streams, and how controls will be managed to protect from unwanted or unauthorized "hacking," public viewing such as on social media.
- Inform and discuss with room-mates, visitors and others if a device is to be used and address concerns.
- Highly encourage the use of signage to inform others that electronic monitoring devices are in use.



Ongoing Discussion

- O What's the "why" behind the request to use an electronic monitoring device?
- Electronic monitoring devices should always be a resident benefit, never a substitute for personal visits and engagement.
- Electronic monitoring devices should never replace a person who is vigilant and care that is individualized and caring.
- Conversations about device use should be continuous, and with all involved.
- Electronic monitoring device use should be a part of new staff onboarding, including when agency staff are used, so rights and responsibilities are clear.
- Engage the ombudsman if communications aren't clear, discussions need a facilitator, potentially.

Summary

- Reason(s) for use, risks and benefits from all perspectives, with the emphasis on that of the resident.
- O What does the resident understand about the intended use of the device(s), if the request for use isn't the resident's?
- Person-centered planning, this is their home
- Ask: Do you have listening or video devices in your home that you don't control?
- o Can others watch you or listen to you without your permission or control?
- o If you do use these devices, for what purposes do you use them?
- What's your "why?"



Summary

Assess:

- The resident's personal history and preferences regarding photographs, shared images, and social media.
- What is the resident's risk awareness, and do they find the risks to be acceptable?
- The resident's relationship with those requesting the monitoring device.
- O What alternatives might there be to installing video or audio devices?



Resources

Board on Aging and Long Term Care Ombudsman Program

800-815-0015 / http://longtermcare.wi.gov

Disability Rights Wisconsin

800-928-98778 / www.disabilityrightswi.org

Guardianship Support Center

(855) 409-9410 / guardian@gwaar.org

 "Balancing Privacy & Protection: Surveillance Cameras in Nursing home Residents' Rooms," The Consumer Voice

https://ltcombudsman.org/uploads/files/issues/cv-ncea-surveillance-factsheet-web.pdf



More Resources

 "A Process for Care Planning for Resident Choice," Rothschild Person-Centered Care Planning Task Force

https://www.pioneernetwork.net/wp-content/uploads/2016/10/Process-for-Care-Planning-for-Resident-Choice-.pdf

 "Protecting Resident Privacy and Prohibiting Mental Abuse Related to Photographs and Audio/Video Recordings by Nursing Home Staff," CMS Memo S&C: 16-33-NH www.cms.gov/medicare/provider-enrollment-andcertification/surveycertificationgeninfo/downloads/survey-and-cert-letter-16-33.pdf





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