

Balancing Right to Treatment and Care & Substitute Decision-Maker Actions

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Services

Health Monitoring

- Monitoring resident health by observing and documenting changes in each resident's health and referring a resident to health care providers when necessary. (AFH)
- The assessment of physical, functional and cognitive status to detect changes that may indicate health problems and to facilitate appropriate intervention. (RCAC)
- The CBRF shall monitor the health of residents and make arrangements for physical health, oral health or mental health services unless otherwise arranged for by the resident. (CBRF)

Resident Rights

Choice

- To choose which services are included in the service agreement, including the right to refuse services provided that the refusal would not endanger the health or safety of the other tenants. (RCAC)
- Participate in the planning of care and treatment, be fully informed of care and treatment options and have the right to refuse any form of care or treatment unless the care or treatment has been ordered by a court. (CBRF)
- To receive all treatments prescribed by the resident's physician and to refuse any form of treatment unless the treatment has been ordered by a court. The written informed consent of the resident or resident's guardian is required for any treatment administered by the adult family home. (AFH)

Self-Determination

- Make decisions relating to care, activities, daily routines and other aspects of life which enhance the resident's self reliance and support the resident's autonomy and decision making. (CBRF)
- To make reasonable decisions relating to activities, daily routines, use of personal space, how to spend one's time and other aspects of life in the residential care apartment complex. (RCAC)
- To have opportunities to make decisions relating to care, activities and other aspects of life in the adult family home. (AFH)

Prompt and Adequate Treatment

- Receive prompt and adequate treatment that is appropriate to the resident's needs (AFH/CBRF)

Residents' Rights

- Are the foundation for all of “our” work, but also the foundation for all of life’s choices, regardless of who you are or where you live.
- Are guaranteed by state and federal laws.
- Direct that everyone – staff, families, volunteers, visitors – are required to respect, protect and promote an individual’s rights.
- Guarantee that every person has the right to exercise all of her or his rights free from interference, coercion, discrimination or retaliation.
- The foundation of Resident Rights states that each person has the right to be treated as an individual, with courtesy, respect and dignity at all times and under all circumstances.

Residents' Rights

- The right to speak confidentially with an advocate is not dependent on a person's decision-making or cognitive status, and must be promoted without coercion or threat of retaliation of any kind.
- Quality of care is provided to enable persons to attain and maintain highest functional capacity.
- Rights insure the freedom of choice in care and treatment decisions, including being able to consent to or decline, with best possible information, any proposed treatment.
- Rights insure personalized care based on thorough and ongoing evaluation, communication and a dynamic care plan.
- Residents cannot be required to have a POA-HC or any other advance directive in order to move into a long term care setting.

Provider Rights

- Accurate pre-assessment information, from all appropriate parties, in order to commit to caring for a new resident.
- Ability to develop a skilled and person-centered care team in order to facilitate necessary discussion and continuous care planning. The resident leads this team, regardless of decision-making or cognitive capacity.
- Access to necessary and appropriate medical providers and services to meet any unique needs or desires of the resident, including those with expertise in specific areas such as dementia, mental health, chronic conditions.
- To be compensated as per an admission agreement, for services provided, and to enact remedies, as may be necessary, under the guidance of the appropriate administrative code.

Substitute Decision-Maker Rights

- The right to speak confidentially with an advocate on behalf of a resident without coercion or threat of retaliation of any kind.
- The right to expect that directives made by or on behalf of a resident, via a POA-HC document or an order of guardianship, will be respected by all involved in that resident's care and treatment.
- The right to participate, at the request or on behalf of a resident, in a skilled and person-centered care team in order to facilitate necessary discussion and continuous care planning. The resident leads this team, regardless of decision-making or cognitive capacity.

Limitations of Substitute Decision-Makers

- *“Nothing about me without me.”* A resident’s wishes must, by statute, always be considered in decisions made on their behalf, regardless of having been deemed incapacitated or incompetent.
- MCO’s and/or county case managers are not surrogate decision-makers in the legal sense, but are essential brokers for services and supports. Surrogate decision-makers may not defer decisions to an MCO or other case manager.
- Providers must understand the boundaries of substitute decision-makers:
 - POA’s for health care make health care decisions only, and then as the resident would choose to make the decisions, if able
 - Guardians make decisions in the best interest of the resident, but always taking into consideration the resident’s preference, if known or able to be expressed.

Ombudsman Issues – POA-HC

- Resident's child or spouse assumes she or he is the resident's decision-maker by virtue of the family relationship, or if they are in possession of a POA-HC document, even though it hasn't been activated.
- Persons above refuse to follow the directives of the resident as noted in the POA-HC document, especially when applied to end of life care {*"I'm just not ready to let her go."*}
- Persons above try to limit visits of others, or deny contact with specific others.
- Persons above ask a resident's MD to de-activate the POA-HC so resident can move into an RCAC or sign a financially-binding contract, such as the sale of a home.

Ombudsman Issues - Guardian

- Resident's spouse claims to be able to force a sexual relationship on the resident because he is not only the spouse but also the guardian.
- Guardian denies physician-ordered care or treatment, or orders the home to provide treatment that would violate a resident's right to choose or decline *{i.e., refuses to allow pain meds, hide meds in food, encourage staff to use tone that could be verbally abusive}*
- Guardian imposes her or his own values on the resident. *{Refuses to give resident any spending money "because she'll just blow it at the casino."}*
- Guardian directs the home to limit visits of others, or deny contact with specific others.
- Guardian refuses to consider the resident's request to live somewhere else without listening to resident's preferences, assessing options.

The Dignity of Risk

- What if you could never do something again because of a mistake you made a long time ago?
- What if you spent three hours every day just waiting? For the bathroom, to smoke, to eat...
- What if your money was always kept in an envelope where you couldn't get it when you just wanted to see how much was there?
- What if people asked you to make a decision, but still did it their own way anyway and didn't tell you why?
- What if you never *got to* make a mistake?
- What if the only risky thing you could do was to act out?
- What if you never got a chance? To...

About Self-Determination

- Younger individuals: risk may be assessed and negotiated on the basis of current skills and potential to learn new skills, goals for future, often leading to higher degrees of acceptable risk with good wrap-around of supports
- Older individuals: risk may be assessed and negotiated on the basis of history and deficits, often leading to denial of request for risk, and at most extreme, imposition of guardianship in order to “protect”

Reducing risk

- Individualized assessments and fluid care planning
 - Ongoing assessments, monitoring & education
 - Practice, refine, practice based on possible alternatives
 - Attempt short term or modified opportunities instead of denying the whole choice.
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- Some of the toughest choices are those in which the individual would decide to choose freedom over safety. Appropriately negotiated risk could accomplish both.

Summary

- Residents/Tenants have rights.
- Decision-makers, care providers and MCO's have responsibilities.
- All must respect and protect residents' rights.
- “Nothing about me without me:” the resident always has a voice that can and must be heard.

Resources

- Guardianship Support Center
(855) 409-9410
guardian@gwaar.org
- Board on Aging and Long Term Care Ombudsman Program
800-815-0015
<http://longtermcare.wi.gov>
- County Adult Protective Services units

Questions