

ADVOCACY IN ETHICAL ISSUES:
A MULTI-DISCIPLINARY
APPROACH

A GUIDE FOR OMBUDSMEN

A Technical Assistance Paper

by

Carolyn Wanner
National Long Term Care Ombudsman Resource Center

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I. INTRODUCTION

Ethical issues concerning residents can be equated to the endless peeling of the proverbial onion - one skin after another - or possibly confronting a multi-headed serpent. Ombudsmen are challenged to consider many complexities, vantage points and variables, if the "authentic" desire of the resident is to be realized. Ombudsmen should take into account the:

Autonomy and Values of the Resident
Communication Difficulties of the Resident
Variations in Learning and Processing Information by the Resident
Conflict Resolution and Group Process
A Framework of Ethical Principles
The Ombudsman Role and Code of Ethics

The list goes on and on. One could begin to feel overwhelmed, but if each issue is addressed, one step at a time, one fact after another, a building process emerges that can facilitate a resident-directed resolution. Previous papers on ethics have addressed these issues and will be listed as a resource in the bibliography at the end of this paper.

II. PURPOSE

Ginny Fraser, State Ombudsman of Colorado, who also holds the title of "most years in the job," suggests that an ombudsmen "...be an attorney, a nurse, a social worker, and all other roles" that impact the resident's life. Since this laudable goal is not possible and ombudsmen cannot be experts in every area, they, instead, can utilize experts in behalf of the resident. Also, they can become "super sleuths" when trying to assist residents in ethical dilemmas.

This paper focuses on the plenary session at the 1994 State Long Term Care Ombudsmen Conference in San Antonio, Texas, entitled "Advocacy in Sticky Situations." Through discussion of a case study, the wisdom derived from presentations by the panel of experts inclusive of a response from the Colorado Ombudsman, and the valuable discussion of ombudsmen in small groups, it is hoped that ombudsmen will be able to:

1. **extrapolate from this case example a process that can be applied to other ethical dilemmas;**
2. **develop an appreciation for and usefulness of the insights and expertise each discipline offers - always with the major thrust in the problem-solving process being "the authentic desire of the resident;" and,**
3. **develop necessary program management for optimum ethical decision-making for residents**

III. CASE STUDY AND PANEL HIGHLIGHTS

Mrs. Jessie Jones has been a resident of the Armadillo Nursing Home for the last two years. She had walked into the nursing home accompanied by her daughter, son-in-law and two of their four grandchildren with whom she had been living for the last year. Prior to that, she had lived in New York State in senior retirement housing near her son and younger daughter. Her husband had died ten years before. She had a grand-motherly appearance and her daughter said she had been a wonderful mother, homemaker, a pillar of her church.

Mrs. Jones came to the nursing home due to the symptoms of multi-infarct dementia - she could no longer be left alone by her family. She had high blood pressure and adult onset diabetes.

Recently, she began to lose interest in eating. In fact, she pushes away the nurse aid who tries to assist her with eating every day. A feeding tube is being considered. The children are divided. The daughters favor "comfort care." The son insists on a feeding tube. Mrs. Jones can no longer talk and has no advanced directives.

The Panel, composed of a social worker, dietician, nurse, speech pathologist, and attorney, (the physician was unable to get there in time) agreed on certain common elements as a place to begin assessing the situation:

- Review of resident's complete Medical Record/Chart.
- The Minimum Data Set (MDS) with accompanying triggers and Resident Assessment Protocols (RAPS) must be critically reviewed prior to any decision-making.
- Obtain more information from any relevant party before a decision is made.

Individual focus, as would be expected, differed depending on the expertise and vantage point of the panelist. Some panelists brought up ideas that crossed disciplines and they are included under the specific panelist if not mentioned by the relevant discipline.

Their comments follow:

Ann Gallagher, Dietician

Resident may not want to eat for a variety of reasons:

- Tasteless, low sodium diet due to high blood pressure
- Low sugar diet due to diabetes
- Medications that impact feelings of hunger
- Discomfort in mouth (bad fitting dentures, sores, decaying teeth)
- Death of family or friend
- Room or roommate change
- Change in the dining room

Treatment:

- Small, frequent meals
- High calorie foods
- Past food preferences
- Different consistencies of liquids and solids, textures
- Different temperatures
- More pleasant environment for meals
- Quiet, music, slowness
- Same nurse aide available - good feeding skills

Lori Larrieu, Speech Pathologist

Indicators for Dyshagia Screen:

- Weight loss of 5% in last month
- Upper respiratory infection in last year
- Two urinary tract infections in last year
- Refusal to eat
- Frequent, persistent cough
- Unable to cough
- Drooling
- Slurred Speech

Possible Interventions:

- Perform fluoroscopy to determine swallowing capacity.
- Work with Dietary to provide best foods.
- Educate staff on proper positioning.
- Develop and implement swallowing strategies.
- Short-term tube approach emphasizing healing (acute aphasia, extreme weakness, imminent dehydration, malnutrition, aspiration).
- Long-term tube approach (dysphagia not treatable without extreme discomfort, silent aspiration).

Weigh Alternatives: Resident could die from starvation if refuse tube; Resident could die from combined medical problems of dysphagia (urinary tract infections, pneumonia).

Pat Nolin, Social Worker

Issues to consider:

- Need to understand and communicate resident's thoughts and concerns.
- Consider depression, other psychological cause.
- Social considerations (personality conflicts with table mate, unpleasant, disruptive environment).
- What is resident's capacity to decide?
- At what point is M.D. involved since she/he writes order?
- Is tube temporary?
- What are underlying interests of children - do interests correlate with resident's autonomy, values, history?

Possible Interventions

- Advocate for self-determination for resident as first consideration.
- Assist resident in executing directives if competent.
- Counsel family to understand resident values, perspective and history.
- Act as counselor to assist children in clarifying questions to other disciplines, weighing pros and cons of tube feeding or less obtrusive options.

Donna Hansen, Nurse

Issues to Consider:

- Assess who needs to be involved, what disciplines.
- Assess care givers, both in terms of their knowledge of resident's needs and desires, and their own involvement.
- Dementia/Cognition - does resident forget to eat?

Suggestions

- Look for some level of capacity -do doctor's notes indicate some thread of consistency about her wishes; can she tell you anything about her life.
- Explore legal actions that assure residents's wishes are met--were there previous discussions with family, surrogate decision maker? Try to avoid guardianship because it may split family and not lead to resident-focused decision.
- Focus on M.D. as Gatekeeper - he writes the orders. Be aware that studies indicate that majority believe nasogastric tubes are "ordinary" vs. "extraordinary" care.
- Get ethics committees involved to guide staff regarding legal responsibility.

IV. OMBUDSMAN RESPONSE

Ginny Fraser, set the tone for the small group work by stressing that:

- There are seldom clear answers.
- We must be comfortable with "process" and "ambiguity."
- Our role as ombudsmen for ethical issues is essentially the same as for other concerns:

Investigator - What are the facts, issues, players, divergent interests, values of resident; get necessary permission to move forward.

Broker - Bring people together or refer to appropriate source; should there be a care plan meeting, family conference, ethics committee input.

Mediator - Help resident or family find an acceptable solution or resolution to complaint or grievance; take note of any unequal power relationships; check personal value system for biases; can a balance be struck between individual autonomy, personal values and best interests; are there creative alternatives/options?

Advocate - Work strictly on behalf of resident but ask same questions as in mediation; make certain decision is resident-focused and consistent with resident's values, past history; is the resident free from coercion; if substitute decision maker--is she fully informed, are there cultural differences that come into play?

Educator - May be narrow or broad but focuses on bringing information to all parties, including educating yourself; inform about laws, regulations (are they

in conflict with facility policies); bring to larger community if necessary.

V. SMALL GROUP DISCUSSIONS

Much of the discussion in groups focused on the issues and roles reflected in Ginny Fraser's response to the panelists. Program management should provide a clear, step-by-step process by which ombudsmen and volunteers can check themselves along the way. Specifically, Ombudsmen must:

► Develop a state protocol which:

1. Determines potential "appropriate role" for local ombudsman, including volunteers.
2. Establishes a "chain of command" for communication at beginning and throughout investigation. When does a volunteer contact local ombudsman, who, in turn, contacts state ombudsman for assistance/guidance? At what point, is case referred to next highest level? At what point are outside parties consulted?
3. Includes language that states ombudsmen can never be "decision-makers" - simply a facilitator that makes sure the decision reflects the residents' wishes, values, history.
4. Includes language that if an ethics committee exists, ombudsmen cannot serve on the committee but may be a resource to it.

► Provide adequate training so that local ombudsmen or volunteers can safely investigate sticky issues:

1. Turn to professional network for training.
2. Work with surveyors.
3. Acquaint trainees with the Values History Form.

► Develop state structures to facilitate state-wide consistency in decision-making.
These may include:

1. Developing a multi-disciplinary team that can provide “expert advice” to ombudsmen. This team can be a significant resource for:
 - (a) clarifying technical information;
 - (b) providing ideas to the ombudsman, if the interdisciplinary team at the facility reaches an impasse, runs out of ideas, or a specific discipline dominates decision-making; and
 - (c) reassessing decision made by facility ethics committee, if nursing home has one, when elements of bias are present.
2. Initiating State law and regulations that are “resident-centered.”
3. Developing or utilizing State or regional ethics committees as a resource.
4. Developing model facility policy that reflects the Patient Self-Determination Act, that ombudsmen can share with homes who are struggling with sticky issues.
5. Developing a model manual covering law, ethical principles and responsibilities involved in the decision-making process (Midwest Center for Bioethics produced one in Missouri); Colorado (Ginny Fraser) developed one based on that model entitled “Guidelines for Making Treatment Decisions for Persons in LTC Facilities.”

VI. CONCLUSION

As the intricacies of sustaining life - whatever that means - become more and more sophisticated and subject to interpretation, ombudsmen will find that the resident advocate role is best served when the necessary ingredients are in place. State protocols for ombudsmen, accompanied by adequate training and adequate state structures, will not provide ombudsmen with all the answers, but will enable them to ask all of the right questions.

VII. RESOURCE BIBLIOGRAPHY

1. Guidelines for Making Treatment Decisions for Persons in Long-Term Care Facilities. (1994) 71 pages.
(Resource manual developed by the Governor's Commission on Life and the Law and published by the Colorado Department of Health. Includes ethical principles, guidelines, a decision-making tree, sample advanced directives, values history form and more. Manual was based on Missouri's good work.)
2. Colorado Law for Medical Decision-Making. (1993) 14 pages.
3. Minnesota State Ombudsman Procedure in Medical Treatment Decision Cases. (1992) 3 pages.
4. Considerations Regarding Life Prolonging Treatment for Residents of Long-Term Care Facilities - A Task Force Report. (1992) 66 pages.
(Resource manual developed by the work of the Missouri Long-Term Care Task Force which was convened by the Midwest Bioethics Center.)
5. Applying Ethical Principles to Individual Advocacy. (June 1992) 14 pages. (Contains summary of Dr. Joan McGiver Gibson's presentation at 1992 National Ombudsman Training Conference.)
6. Working Through Ethical Dilemmas in Ombudsman Practice. (1989) 93 pages. (Contains a resource paper and training guide by Sara Hunt.)