

## **Residents' Rights and Surrogate Decision Making**

12/3/08 Audio Conference

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**Our topic today is Residents' Rights and Surrogate Decision Making. I am Susan Johnson, Project Manager of Virginia SMP Program. With me today is Gail Shirley, Assistant State Long Term Care Ombudsman, and Kathy Pryor, Elder Law Attorney with the Virginia Poverty Law Center. The format today will be conversational questions and answers between me, as facilitator, and the presenters, Gail and Kathy. We will begin with an overview of residents' rights which will be followed by surrogate decision making, with a time for participant questions at the end.**

**Q: Gail, I've heard the term 'resident's rights', but what exactly are they?**

A: As you know, we all have basic human rights and civil rights that we often take for granted. For example, most of us take the simple things-- like visiting with whomever we want to and getting up and going to bed when we want to-- for granted. Just because you move into a nursing home, doesn't mean that you lose your basic rights. In fact, residents of nursing homes have additional rights under state and federal laws that are specific to the status of being a resident. The legal basis for residents' rights is found in the Omnibus Budget Reconciliation Act of 1987, (also known as OBRA '87); federal regulation is also found in the Medicare and Medicaid Requirements for Long Term Care Facilities, and state regulations, mirroring the federal ones, are found in the Code of Virginia (Va. Code § 32.1-138).

There are 2 key provisions in the regulations that form the basis of residents' rights and they are -- Quality of Care and Quality of Life.

Quality of Care says "... the facility must provide the necessary care and services to attain or maintain the highest practicable physical, mental and psychosocial well-being of each resident..."

Quality of Life says a nursing home must care for residents in such a manner and in such an environment as will promote maintenance or enhancement of the quality of life of each resident.

**Q. Quality of care and quality of life is what we all want. I've heard that the quickest way to send someone into depression is to take away someone's rights to make choices about the course of his or her own life....**

A. Yes, I think that's true. That's why it is so important that residents' rights are spelled out in federal and state law to safeguard and promote residents' dignity, choice, and self-determination.

**Q: I understand that residents' rights are set in law with the general principles to protect quality of care and quality of life, but can you explain what specific rights nursing home residents have?**

A: First, for your own empowerment, it is important for all residents and their families to have a copy of the residents' rights. You can obtain a list of residents' rights from the nursing home. The facility is required to give you a copy upon admission and later if you request one. You may also want to go to the National Citizens' Coalition for Nursing Home Reform's (known as NCCNHR) website at [www.nccnhr.org](http://www.nccnhr.org) and look at the Consumer Fact sheets for a copy of residents' rights and related materials. Let me give you a quick overview:

Residents have rights regarding health care:

They have the right...

- To be free of restraints;
- To have their choice of physician;
- To participate in their treatment/care planning;
- To refuse treatment; and
- To be transferred or discharged only after reasonable written notice and only for medical reasons, the safety or welfare of other residents,

or for non-payment....and if those conditions are met, to have an appropriate discharge plan to meet their specific needs.

**Q: The right to be free of restraints... If a resident has repeated falls or starts wandering into other residents' rooms or even out the door of the facility, can the facility use physical or chemical restraints to prevent the resident from falling or wandering?**

A: Only if restraints are necessary to ensure the physical safety of the resident or other residents and, except in an emergency, only with a written order of a physician which states the duration and circumstances under which restraints may be used. Physical restraints include a vest or belt that ties the resident to a wheelchair or bed, or a bedrail; a chemical restraint is a behavior-modifying or psychoactive medication. Federal law states that the resident has the right to be free from chemical or physical restraints which are not necessary to treat their medical symptoms. Restraints should never be used for the convenience of staff or to discipline the resident, but only to treat the resident's medical symptoms. Physical restraints have actually been shown to cause harm, such as falls because the resident has become more unsteady or tries to climb over a bed rail, asphyxiation from entanglement in the restraint, pressure sores, or depression or agitation from being tied to a chair. Often, other alternatives are safer and more effective than restraints. For example, scheduling an aide to walk with a resident a couple times each day may reduce wandering. A resident who is experiencing falls may need a walker or staff support when walking. For more information on restraints, see the fact sheet on restraints developed by NCCNHR at [http://www.nccnhr.org/public/50\\_156\\_451.cfm](http://www.nccnhr.org/public/50_156_451.cfm).

**Q. You also mentioned the right to refuse treatment and discharge rights that we have discussed in an earlier audio conference. If I understand you correctly, you're saying that, according to residents' rights, if my mother refuses to take a medication the doctor has prescribed because it makes her groggy and unsteady, that is within her rights under the law? If the nursing home claims that she has to go to another nursing home because they can't meet her needs if she refuses this treatment, this is not legitimate. Is that right?**

A. That's right....a resident's refusal of treatment is not a reason for discharge. There are only 6 legitimate reasons for discharge (and exercising

one's right to refuse treatment is not one of them!). As a reminder, the 6 reasons are:

1. failure to pay;
2. the resident no longer needs nursing home care;
3. the resident's needs cannot be met in this nursing home (for example the resident needs a respiratory therapist on staff and the nursing home does not have one.... exercising one's right to refuse treatment does NOT mean the nursing home cannot meet your needs);
4. the resident's presence endangers others' safety;
5. the resident's presence endangers others' health;
6. the nursing home is going out of business.

**Q. Please tell us more about specific residents' rights:**

A: Residents have the right to Exercise Individual Liberties:

- To exercise rights as a resident and a citizen;
- To complain and make suggestions without fear of retaliation;
- To a dignified existence and self-determination;
- To be free of verbal, sexual, physical and mental abuse;
- To participate in social, religious, and community activities of their choice;
- To have their own and use their own clothing and possessions (as space permits);
- To manage their own personal business affairs; or, if this is delegated to the nursing home, then to receive an accounting every 3 months or on request;
- To have access to visitors, family, friends and representatives of certain agencies of their choice; and
- To share a room with their spouse, if both are residents and both consent.

**Q: You said residents have the right to complain and make suggestions without fear of retaliation. I've heard residents and family members express fear that if they complain, the nursing home will retaliate against them. Is this fear justified?**

A: The fear is reasonable since, unfortunately, this does sometimes occur, but such retaliation is forbidden by federal law. A resident has the right to voice grievances about his or her care without discrimination or reprisal and has the right to expect the facility to act promptly to resolve the complaints.

In addition, a resident and her family have the right to organize and to participate in resident or family councils, to have those groups meet in the facility, and to expect the facility to listen to and act upon the complaints and recommendations made by the residents and families about policies and operational decisions affecting resident care and life in the facility. If you fear retaliation, sometimes it's helpful for the problem to be presented to the administration through a 'group' complaint, so to speak, from the resident or family council. For more information about family councils, go to the NCCNHR website at <http://www.nccnhr.org>.

**Q: What about the third right you just mentioned ... “the right to a dignified existence and self-determination.” That is not something we always see that when we visit in a nursing home.**

A: Rights to dignity...how staff treat residents is an extremely important part of their care. To be spoken to like an adult and to be treated courteously with kindness and respect, and dignity makes a resident feel like a human being rather than a task to be completed or an object.

Self-determination seems contrary to the institutional care approach that we often see. These rights require the nursing home to adapt to each resident's routine preference instead of the residents adjusting and conforming to the nursing home's schedule!

The law says residents can choose activities, schedules and care consistent with their interests, assessments and plans of care.

The law also says residents are to reside and receive services with reasonable accommodations of their individual needs and preferences by the nursing home.

**Q: What does “reasonable accommodation of individual needs and preferences” mean?**

A: It should mean, for example, that different residents should have different schedules for eating and bathing, based on the individual resident's preferences. A person who has always stayed up late at night and slept late in the morning should not suddenly be forced to get up at 6 a.m. to be bathed and dressed because that is the time convenient to staff. A resident who hates crafts but loves gardening should not be forced to go to a craft activity but should have the opportunity to garden in some manner.

The need to accommodate individual needs and preferences can be more complicated when the health or safety of other residents is impacted. For example, how does a facility accommodate the needs of a resident who smokes without endangering the health and safety of other residents? Usually the needs of both groups can be accommodated. For example, the resident may not be allowed to smoke in his room or in certain other parts of the building, but the facility may designate a smoking area for residents who wish to smoke.

**Q: So a nursing home should not treat everyone the same since residents are individuals with different needs and preferences?**

A: That's right. A resident has the right, under federal law, to receive services "with reasonable accommodation of individual needs and preferences except where the health or safety of the individual or other residents would be endangered." This includes the right to choose activities, schedules and health care which are in line with the resident's interests, assessments and plan of care.

**Q. Are there any additional residents' rights?**

A: Yes, residents also have rights to information:

- To be informed of their rights, and the rules and regulations of the nursing home;
- To receive prompt efforts to resolve grievances;
- To have any significant change in health status reported to him or her;
- To be informed of their condition and planned medical treatment and to participate in planning or refusing that treatment;
- To examine the results of the most recent nursing home survey;
- To be informed of bed reservation policy if they're hospitalized; and

- To be told of all services available and whether charges are covered or not.

In addition, residents have rights to privacy:

They have the right....

- To personal privacy in medical treatment and personal care;
- To send and receive unopened mail;
- To receive visitors in privacy;
- To have their personal and medical records treated confidentially; and
- To have reasonable access to the use of a telephone where calls can be made without being overheard.

**Q. It seems that many people fear the lack of privacy upon entering a nursing home. Doesn't a resident give up rights to privacy when he or she moves into a nursing home?**

A: No. Federal law protects a resident's right to privacy in written and telephone communications, accommodations, medical treatment, visits, meetings of family and resident groups, and to confidentiality of personal and clinical records. A resident does not have the right to a private room, but a married couple does have the right to share a room if they reside in the same facility and both consent.

Privacy includes rights to privacy with whomever the resident wishes to be private...from medical treatments to bathing, to visual privacy, to auditory privacy, and for visits or other activities to the extent desired.

**Q: You said a resident has the right to receive visitors. Can a nursing home limit visiting hours for a resident's family members?**

A: No, not unless the resident denies or withdraws consent for the immediate family or other relatives to visit. Otherwise, federal law allows immediate access to the resident by an immediate family member or other relatives. Of course, the family should be sensitive to the needs of the resident's roommate and other residents and may need to visit somewhere other than the resident's room if the roommate is sleeping.

**Q: What rights does a resident have with regard to access or visitation by people other than family members?**

A: The resident's physician and certain agencies must have immediate access to the resident without limitation. The nursing home must permit immediate access, "subject to reasonable restrictions," and subject to the resident's right to deny or withdraw consent to others visiting. Anyone who provides health, social, legal or other services to the resident must be given reasonable access.

**Q: We've covered quite a bit of information on Residents' Rights in a short amount of time. What would you say is the most important thing to know or to remember?**

A: It is important to know that upholding residents' rights is a process; it is not something that is done once, checked off a list and forgotten because it is a standard that has been met.

It is important to know and to remember that residents retain their basic right to be in control of their lives.

**Q: Well, that certainly raises another question! Kathy, let me turn to you. If residents generally have the right to be in control of their lives, what happens when residents are impaired? Who gets to make those decisions then—the nursing home resident himself, or his responsible party or family member?**

A: Generally, the resident should be able to make those decisions himself. A resident is presumed to be able to make his own decisions unless a guardian or conservator has been appointed for him by the court. If a guardian or conservator has been appointed, then the resident's rights which Gail has described can be exercised by the person appointed as his guardian or conservator. Even where a guardian has been appointed, the resident may be able to make certain decisions for himself.

**Q: What is the difference between a guardian and a conservator? Can one person be appointed as both guardian and conservator? Does a person found to be incapacitated necessarily need both?**

A: A guardian is a person appointed by the court to handle the personal decisions for the incapacitated person—decisions about where the person is to live, what care and support he needs, decisions about health care, etc. A conservator is a person appointed by the court to manage the person’s estate and financial affairs—to pay the person’s bills, handle his bank accounts, deal with real estate, etc.

One person can be appointed as both guardian and conservator, or the court could appoint two different people, one to handle the finances and the other to make personal decisions. Sometimes, the incapacitated person does not need both. For example, the now-incapacitated person may have already named an agent through a power of attorney to handle his financial matters. Unless there is reason to think that that person is not acting in the incapacitated person’s best interests, then the agent may continue to act in that capacity and if he were authorized under the POA to handle all the person’s financial matters, there would be no need for a conservator to be appointed. Similarly, if the person had already named an agent to make medical treatment decisions in case he became incapable of making those decisions in the future, then the health care agent may be sufficient-- if the only need was for someone to consent to surgery, it may not be necessary for a guardian to be appointed.

**Q: What is the process for having a guardian or conservator appointed?**

A: A petition must be filed in the circuit court where the alleged incapacitated person resides or where he last resided before admission to the nursing home. Any person can file a petition for the appointment of a guardian or conservator. The law requires that certain information be included in the petition. An attorney must be appointed as guardian ad litem (GAL) to represent the interests of the alleged incapacitated person. The GAL must visit the person, advise him of his rights, and must investigate the petition, make an independent evaluation and report to the court about whether, in the GAL’s opinion, the person needs a guardian or conservator, whether the person seeking appointment is appropriate, what limitations there should be on the powers given the guardian or conservator. In addition, there must be a medical evaluation and report filed with the court about the condition of the person for whom guardianship is sought. Various family members must receive copies of the petition and must be notified of

the hearing. The alleged incapacitated person must be served with a copy of the petition and notice of his rights and of the consequences of a guardian or conservator being appointed. He has the right to be represented, to be present at the hearing, etc. After hearing evidence at the hearing, the circuit court judge will determine whether a guardian and/or conservator should be appointed and, if so, will sign an order appointing the guardian/conservator and setting out the authority the person is granted and what rights are retained by the incapacitated person.

This is a fairly involved process which takes time and can be expensive. If a guardian or conservator is appointed, the incapacitated person loses some of her rights so it is not something to be done lightly but only when absolutely necessary and when other less restrictive alternatives are not available.

**Q: What has to be proven in order for a guardian or conservator to be appointed by the circuit court?**

A: In order for a guardian or conservator to be appointed, the court must find, by clear and convincing evidence, that the person is incapable of receiving and evaluating information effectively or responding to people, events or environments to such an extent that the individual lacks the capacity to meet the essential requirements for his health, care, safety or therapeutic needs without the assistance or protection of a guardian; or lacks the capacity to manage property or financial affairs or provide for his support or the support of his legal dependents without the assistance or protection of a conservator. Poor judgment alone is not sufficient evidence that the person is incapacitated. Generally, a finding by the court that the person is incapacitated is considered to be a finding that the person is mentally incompetent unless the court order provides otherwise.

**Q: Once a guardian or conservator is appointed, does the guardian or conservator make all the decisions for the resident? What rights does the resident have once a guardian is appointed for her?**

A: First, you would want to review the court order appointing the guardian or conservator. The order should specify what authority the guardian or conservator has been given. The law says that both a guardian and a conservator should encourage the incapacitated person to participate in decisions and to act on his own behalf to the extent feasible. So there is generally an effort to reserve as much decision making authority to the

resident as possible. For example, a resident with a guardian may not be able to decide to move out of the nursing home without the agreement of the guardian, but the resident should be able to decide whether to engage in certain activities, whether she wants a particular person to visit or not, when she wants to have her bath, etc.

The guardian/conservator is supposed to try to make those decisions which the resident would have made if she were now capable of making decisions. If the resident has clearly expressed her wishes on some matter while she was competent, the guardian generally should honor those expressed wishes. Only when the guardian does not know what decisions the resident would have made is the guardian supposed to substitute the guardian's own judgment based on what she believes is in the resident's best interests.

**Q: What if there is no guardian but an adult child has been named as the resident's agent through a power of attorney? Who has authority to make decisions then?**

A: A power of attorney generally authorizes someone to make financial, business-type decisions, not the kinds of daily living decision making we're mostly talking about today. The specific powers an agent has would be set out in the power of attorney document and the agent's authority is limited to those named powers. A power of attorney generally becomes effective when signed. If the power of attorney is durable, it continues to be effective even if the person giving the authority becomes incompetent later. If the resident is no longer able to make decisions for himself, then the agent would still be authorized to make the kinds of decisions authorized in the document on the resident's behalf.

It is important to realize that the fact that a resident has signed a power of attorney does not mean the resident no longer has authority to make his own decisions. The resident continues to have the right to make his own decisions, including the right to revoke the power of attorney document, even if he also has an agent authorized to act for him. If the resident's wishes and his agent's wishes are in conflict, the resident's wishes should prevail as long as the resident is still competent.

**Q: What about health care decision making if the resident has appointed an agent through an advance medical directive or health care power of attorney?**

A: Generally, an advance medical directive does not become effective until two doctors or a doctor and licensed clinical psychologist determine that the person who signed the AMD is not capable of making an informed decision about his health care. Until such an assessment is made, the person is presumed to be capable of making his own health care decisions.

“Incapable of making an informed decision” means that, because of a mental or physical disorder or illness which impairs judgment or precludes communication, the person is unable to understand the nature, extent and probable consequences of the proposed decision or to make a rational evaluation of the risks and benefits of alternatives to that decision.

If a person is found to be incapable of making an informed decision, then the named agent is supposed to base her decision on the patient’s known religious beliefs, basic values and previously expressed preferences. If the agent cannot determine what decision she thinks the patient would have made, then the agent should decide what decision or treatment she thinks is in the patient’s best interests. The agent should never make any decision about treatment which she knows is contrary to the religious beliefs or basic values of the patient.

Even if a resident is found to be incapable of making an informed decision at one time, he may be fully capable of making an informed decision at another time. If so, the resident would make his own health care decisions and the agent would not have authority to make health care decisions at that time.

**Q: What if either a guardian or an agent appointed under a power of attorney or advance medical directive is acting against the expressed wishes of the resident or contrary to the best interests of the resident?**

A: The court which entered the original guardianship order can also modify or terminate the guardianship or can find that the incapacitated person is no longer in need of a guardian and restore the person to capacity. If the court finds that the guardian or conservator is not acting in the best interests of the incapacitated person, the court could limit the powers of the guardian or

conservator, could order a new bond, or could remove the guardian or conservator.

If an agent under a power of attorney or advance medical directive is acting contrary to the expressed wishes or best interests of the resident, the resident could revoke the POA or AMD as long as he is still competent to do so. If the person is no longer able to attend to his own affairs, there is a process for a member of the person's family to request records from the agent named in the POA and, if the agent doesn't make a timely response, to petition the court to require discovery of documents necessary to determine whether termination of the agent's authority is warranted or whether there are grounds to bring a proceeding to hold the agent liable for breach of his duty to the resident and to recover assets. See Virginia Code §§ 11-9.6 and 37.2-1018.

**Q: In closing, let me remind our listeners that if they have individual situations they wish to discuss concerning residents' rights and/or surrogate decision making, the best resources to contact are your local legal services and/or your local Long-Term Care Ombudsman. If you do not know which office covers your area, contact 1-866-534-5243 to obtain the number of your legal services program and 1-800-552-3402 to obtain the name and number of the local Long-Term Care Ombudsman in your area.**