

RIGHTS

The federal 1987 Nursing Home Reform Law guarantees Residents' Rights. The law requires nursing homes to ***“promote and protect the rights of each resident”*** and places a strong emphasis on individual dignity and self-determination. Nursing homes must meet federal residents' rights requirements if they participate in Medicare or Medicaid. Some states have residents' rights in state law or regulation for nursing homes, licensed assisted living, adult care homes, and other board and care facilities. A person living in a long-term care facility maintains the same rights as an individual in the larger community.

Residents' Rights Guarantee Quality of Life

The 1987 Nursing Home Reform Law requires each nursing home to care for its residents in a manner that promotes and enhances the quality of life of each resident, ensuring ***dignity, choice, and self-determination.***

All nursing homes are required "to provide services and activities to attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident in accordance with a written plan of care that... is initially prepared, with participation, to the extent practicable, of the resident, the resident's family, or legal representative." ***This means a resident should not decline in health or well-being as a result of the way a nursing facility provides care.***

The 1987 Nursing Home Reform Law protects the following rights of nursing home residents:

The Right to Be Fully Informed of

- Available services and the charges for each service
- Facility rules and regulations, including a written copy of resident rights
- Address and telephone number of the State Ombudsman and state survey agency
- State survey reports and the nursing home's plan of correction
- Advance plans of a change in rooms or roommates
- Assistance if a sensory impairment exists
- Residents have a right to receive information in a language they understand (*Spanish, Braille, etc.*)

Right to Complain

- Present grievances to staff or any other person, without fear of reprisal and with prompt efforts by the facility to resolve those grievances
- To complain to the ombudsman program
- To file a complaint with the state survey and certification agency

Right to Participate in One's Own Care

- Receive adequate and appropriate care
- Be informed of all changes in medical condition
- Participate in their own assessment, care-planning, treatment, and discharge
- Refuse medication and treatment
- Refuse chemical and physical restraints

- Review one's medical record
- Be free from charge for services covered by Medicaid or Medicare

Right to Privacy and Confidentiality

- Private and unrestricted communication with any person of their choice
- During treatment and care of one's personal needs
- Regarding medical, personal, or financial affairs

Rights During Transfers and Discharges

- Remain in the nursing facility unless a transfer or discharge:
 - (a) is necessary to meet the resident's welfare;
 - (b) is appropriate because the resident's health has improved and s/he no longer requires nursing home care;
 - (c) is needed to protect the health and safety of other residents or staff;
 - (d) is required because the resident has failed, after reasonable notice, to pay the facility charge for an item or service provided at the resident's request
- Receive thirty-day notice of transfer or discharge which includes the reason, effective date, location to which the resident is transferred or discharged, the right to appeal, and the name, address, and telephone number of the state long-term care ombudsman
- Safe transfer or discharge through sufficient preparation by the nursing home

Right to Dignity, Respect, and Freedom

- To be treated with consideration, respect, and dignity
- To be free from mental and physical abuse, corporal punishment, involuntary seclusion, and physical and chemical restraints
- To self-determination
- Security of possessions

Right to Visits

- By a resident's personal physician and representatives from the state survey agency and ombudsman programs
- By relatives, friends, and others of the residents' choosing
- By organizations or individuals providing health, social, legal, or other services
- Residents have the right to refuse visitors

Right to Make Independent Choices

- Make personal decisions, such as what to wear and how to spend free time
- Reasonable accommodation of one's needs and preferences
- Choose a physician
- Participate in community activities, both inside and outside the nursing home
- Organize and participate in a Resident Council
- Manage one's own financial affairs

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Nursing Homes: getting good care there

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Chapter 2

Cornerstone of Care: Residents' Rights

"Our physical weakness and mental fatigue have robbed us of much of our independence and often lowered our self-esteem, but we need the opportunity to make more of our own decisions. With our options narrowed as they are, by necessity, it should not follow that so many opportunities are closed to us, or only available after complaints and protest."

-- Elizabeth Wyckoff, nursing home resident and president of the Coalition for Institutionalized Aged and Disabled in New York City when she passed away July 3, 1994

WHAT IS IT THAT PEOPLE FEAR MOST ABOUT NURSING homes? *The prospect of having to yield their freedom, privacy, choice, independence and control.*

It's the "little" things -- savoring an early morning cup of coffee, meeting a friend for lunch, watching a late movie -- that people miss the most if these are no longer possible. Living in a nursing home can completely disrupt lifelong routines, and greatly diminish options for personal choice. Because of these factors, residents need support and encouragement to exercise their rights to make as many decisions about their daily lives as possible.

And that's where you come in.

Why are There Residents' Rights?

The Nursing Home Reform Law and many state laws contain specific provisions that protect residents' rights -- the basic human and civil liberties that most of us take for granted every day. For example: the right to visit with anyone you choose, or the right to get up and go to bed when you wish. Who wouldn't expect to make such decisions? You don't lose any rights when you move into a nursing home.

But nursing home staff tend to focus on routine and efficiency. They must care for large numbers of frail, dependent people. Respect for the rights of individual residents' sometimes gets lost in the drive to operate efficiently as a business.

The nursing home is an institution, with institutional bureaucracy and management. Residents are physically frail and often mentally confused. These factors help explain why the law places so much emphasis on residents' rights.

Residents' rights are one of the key items state survey agencies must inspect during their reviews of nursing homes, and many states have their own strict laws and regulations to protect individual rights. (You can learn more about the survey process in chapter 7, "Problem Solving: Being Your Own Advocate.")

Residents and their families generally receive a copy of a home's policy on residents' rights upon admission. This important document can help residents receive the best possible care. It's a good idea for both residents and family members to reread it from time to time. A summary of federal residents' rights appears in Appendix 3. Be sure the home's policy does not violate rights you are entitled to.

⇒ **TIP** -- If you don't have a copy of the residents' rights, by all means ask for it! Homes also prominently post it.

Let's take a look at some of the major rights guaranteed to residents of nursing homes.

Whose Rights?

Our emphasis here, of course, is on the rights of *residents*. Staff, families and physicians have rights, too, and all have important roles to play. But when a person moves into a nursing home, it's common for everyone *but* the resident to assume a decision-making role. That's unfortunate, because the quickest way to send someone into depression is to seize her right to make choices about the course of her own life. Your role as a family member is to assist your relative in exercising her rights. You fulfill your role best when you look at life from your relative's perspective.

Sadly, many residents are denied their rights by their own inability to make decisions. Experts estimate that more than half of the people living in nursing homes today have some degree of mental impairment. Still, even people who are forgetful or confused can express their needs and wants. Often a resident who needs help with complex matters may be able to make her own decisions about more day-to-day issues. The resident's ability to communicate may be better on some days than on others, but such fluctuations shouldn't interfere with the basic right to express feelings and exercise choice to the greatest degree possible.

Residents Who Can't Choose

Residents who are completely unable to participate effectively in their own care need to have a substitute decision-maker, or advocate, to ensure their rights are protected. A close family member is usually in the best position to understand -- and to help staff understand -- what the resident might say or choose if she were able to express her own preferences. What, for example, is her usual morning routine? What does she normally eat for breakfast? What kind of music does she enjoy?

What are the Rights of Residents?

Under federal standards, residents' rights include the right to:

- receive information
- participate in planning all aspects of care
- make choices and independent personal decisions
- enjoy privacy in care and confidentiality regarding medical, personal or financial affairs
- be treated with dignity and respect
- know personal possessions are safe and secure
- be protected against transfer, unless for specific reasons
- raise concerns or complaints.

Knowing the rights is an important first step, but it's not enough. What's really important is *exercising* these rights. Chapter 7's discussion on problem solving describes the steps to take when a resident or advocate thinks the resident's rights have been violated. That chapter offers information about how, when, and where to call for help and guidance in getting the problem resolved.

In this chapter, the focus is on the rights themselves and what they mean to residents in nursing homes.

The Right to Information

Besides giving residents a copy of their rights on admission to the nursing home, the facility must provide other kinds of information, including material that explains:

- services available in the facility
- state laws regarding living wills, durable powers of attorney for health care and other forms of advance directives, along with the facility's policy on carrying out these directives
- *all* matters related to financial charges, including a list specifically indicating what items are covered by Medicaid or by the daily private-pay rate
- the Medicaid application process

- the amount of money a Medicaid resident has in his/her personal needs account (residents should regularly receive statements with this information)
- how to review the health department's most recent survey of the facility by the licensure or certification agency
- how to examine a resident's medical records (a resident may transfer this authority to another person either through consent or through legal authority).

In addition, the facility also should provide information, including addresses and telephone numbers, on how to reach:

- the state licensure and certification agency
- the local and state long-term care ombudsman
- the area's protection and advocacy organization (the agencies that investigate abuse).

During admission, residents and their families typically receive an enormous amount of new information. You'll want to be able to easily find this information if needed.

⇒ **TIP** -- It's a good idea for friends and families to set up a small filing system to keep track of these important papers and bills.

Here's an example of the right to information regarding charges.

Your mother is on Medicaid. At the end of the first month of her stay in the nursing home, you receive a bill for adult incontinence briefs. Is this cost covered by Medicaid in your state?

Under federal law, the nursing home must provide you information on covered costs. If you pay privately, the facility must inform you of all charges for any services not included in the daily rate.

The Right to Participate in Planning and Care

All nursing home residents are entitled to take part in planning for their own care. (A detailed explanation of the care planning process appears in chapter 3.) Residents have the following rights of participation in this important process:

- to be fully informed, in advance, and participate in making decisions about all care and treatment and any changes in that care and treatment that may affect residents' well-being
- to participate in their own care planning meetings
- to refuse treatment and to receive information regarding appropriate alternatives
- to self-administer medication, unless self-administration has been determined to be unsafe
- to privacy and confidentiality with regard to medical records
- to be free from vest restraints, hand mitts, seat belts and other physical restraints
- to be free from unnecessary antipsychotic drugs, sedatives and other chemical restraints.

Looking at this list you can see the importance of talking with facility staff from the very beginning about your relative's wants and needs. You and your relative need to be involved in assessing needs, setting goals and planning for care. In chapter 3 you'll learn why a care planning meeting is a good time to discuss the issues listed above. Understanding and being vocal in this process are keys to ensuring good care. You can also ask for a family meeting with staff in between care planning meetings.

Generally, nursing home residents are the best judges of their own bodies. Unless severely impaired, residents know when they are thirsty, hungry, or need to go to the bathroom. They know when they don't feel right because of a certain medicine. They know that appropriate movement and exercise, adjusted for ability, builds strength, confidence and a sense of well-being.

Sometimes it's necessary to remind staff caretakers that residents should be in charge of their own bodies. Residents usually can tell the staff caretaker when, and how, to help.

Your father is in the nursing home to recover from a stroke. He tells you that the new medication his doctor has prescribed makes him very dizzy. When he refused to take it yesterday, the nurse became angry and practically forced it in his mouth.

Your father has the right to question the effects of medication and to refuse to take it. This is the time to speak to the nurse or to the doctor on your father's behalf.

The Right to Make Independent Choices

Studies show that one of the most important factors in nursing facility residents' quality of life is the ability to continue to make choices about their own lives. Living in a nursing home does not take away a person's right to an individual schedule. Some activities may be modified but shouldn't jeopardize respect for a resident's preferences. Although the following list isn't spelled out in the law, the right to choice clearly includes:

- getting up and going to bed when a resident chooses
- eating or enjoying a variety of snacks outside of regularly scheduled meal times (within dietary restrictions)
- selecting what to wear
- choosing activities and deciding how to spend time
- receiving a choice in main meals
- managing personal finances (when possible).

Some people have eaten large breakfasts throughout their lives, while others may simply like a cup of coffee, juice and toast in the morning. Some are early risers, others prefer to sleep later. Residents should be able to choose their morning fare and when to wake up and go to bed.

The federal law directs facilities to provide residents "reasonable accommodation of needs." Of course, this mandate does not mean repainting walls to satisfy residents' and families' decorating tastes. But the law does require that the home's activities should meet a variety of interests. It means that food should be prepared to meet individual tastes and needs. Sleep should be interrupted only for necessary care. Residents should be taken -- or able to go -- to the bathroom when they need to go, not just when the time is convenient for staff.

Whenever you visit your mother in the morning, you notice she can hardly stay awake. She says that staff wake her up so early that by 10 a.m. she's worn out. You discover that the nursing assistants on the night shift get her up at 5 a.m. to get dressed. Then she waits in the hall in her wheelchair until breakfast at 8 o'clock!

When you inquire about this situation, you're told that "the day shift doesn't have time to get everyone up."

Staff are out of line here, and should be instructed that your mother has the right to get up according to her own wishes.

The Right to Privacy

The loss of privacy is one of the main fears among people who face living in a nursing home. Moving into a nursing home usually means sharing a room with a stranger. The residents are expected to get along despite differences in their conditions, personalities and, perhaps, culture. The space allocated to each resident is often barely large enough for a bed, small table, and chair. Although curtains may be drawn between the beds, they don't shut out sounds, making private conversations difficult.

Privacy is often lost amid the brisk pace and commotion of the caregiving routine. Staff may enter a room without knocking or waiting for a response to the knock. They might take a resident down the hall to the bath without making sure that the person is fully clothed.

Good care, however, demands a different scene, granting residents specific privacy rights, including the right to privacy in:

- treatment
- caring for personal needs
- visits with family and friends
- communication -- such as when making or receiving telephone calls and sending or receiving mail unopened
- personal matters, such as medical condition and financial affairs.

These required accommodations to residents' basic privacy needs thus provide that there must be a place to make a phone call without being disturbed or overheard, and a quiet place to visit with friends and family. Staff must make sure that doors are closed and curtains pulled during care treatments, and that residents aren't exposed when their roommate has visitors or when they're sitting in the hall or going to the bath. Residents' mail must not be opened without their consent.

When you are visiting your mother in the nursing home, staff members often enter the room and interrupt your privacy. Your mother also tells you that someone is always walking in, even when the door is closed, just when she is dressing or going to the bathroom.

You should bring these problems to staff's attention and remind them that residents are entitled to a knock and an affirmative response before staff members enter the room.

The Right to Dignity

Nursing home residents rank the way staff treat them as the most important factor in their care. Nothing is more valuable to residents than staff who are kind, courteous and respectful. Residents want a well-trained staff whom they can know and trust. They want to receive help when they need it. They want to be spoken to like adults. They want to be treated with dignity.

Your mother tells you that the aide on the 3 to 11 p.m. shift is mean to her. She tells your mother to shut up, and that she doesn't have time to take her to the bathroom again.

You know that the standard of care is that facilities support each resident's quality of life. You also know that the facility must provide care in a way that maintains or enhances each resident's dignity.

You should inform administration about the problem with the aide and ask for their commitment to deal with the situation.

The Right to Freedom of Association

The constitutional right to speak to and associate with whomever one chooses doesn't vanish when one moves into a nursing home. But, sometimes, well-meaning family and staff attempt to interfere with a resident's relationships. Residents have the right to:

- share a room with a spouse
- gather with other residents and resident groups within the home without staff being present
- meet with state and local ombudsmen or any agency providing advocacy or services
- belong to any church or social group
- receive visitors at reasonable hours
- leave the nursing home
- make or receive telephone calls.

An old friend of your mother's comes in to visit her at the nursing home at least once a week. The staff tell you that after every visit your mother seems to be very upset. They think that the friend tells your mother that she doesn't need to be in the nursing home.

The issue here is whether your mother wants to see her friend. If she does, she has the right to see her, whether she is upset or not. Neither the nursing home nor you retains the right to limit visitors.

Rights Regarding Transfer and Discharge

Few aspects of nursing home care can be more traumatic than when a resident is told to leave the home or move to another room. With good reason, families and residents dread these two situations. To have to adjust to a different facility or even to a different room and roommate usually is disruptive and distressful for everyone.

Facilities are required to follow specific procedures for transfers and discharges. You can minimize the distress of a transfer by making yourself aware of the rights of residents -- and the policies of the facility which should reflect the law -- regarding transfer and discharge.

Reasons for Transfer or Discharge. Transfers are permissible only under certain reasons and conditions. These include:

- when the resident's health or safety is endangered in the facility
- when, after reasonable notice, a bill for care remains unpaid
- when it is necessary for the resident's welfare because the resident's needs cannot be met in the nursing home

- when it is appropriate because the resident's health has improved enough that the resident no longer needs the facility's services.

Notification. Before a resident can be transferred, the facility must notify the resident, family member or legal representative in writing. The facility must give the *reasons for the move* and *30 days' notice*, except in certain emergencies. The notice must include:

- a statement indicating that the resident has a right to appeal this action
- the name, address and telephone number of the state *long-term care ombudsman*.

(A note to residents of sub-acute/short term units: Even if you signed admission papers agreeing to transfer when your Medicare coverage runs out, you are entitled to contest the transfer at a hearing. Talk to your ombudsman for assistance.)

The facility must assist the resident to prepare for the move and provide whatever services are necessary to protect the resident's safety and arrange for an appropriate plan after discharge.

Room-to-room transfer. A facility may ask an individual to change rooms for a variety of reasons: to resolve roommate issues, to accommodate a new resident, because of a change in the resident's level of care or source of payment.

Even a transfer to a nearby room can be exceedingly difficult when a resident has become familiar with her particular space and place. Typically, a resident doesn't have the same right of appeal as in the case of a transfer out of the facility. However, the facility must accommodate the needs of each particular resident and residents have the right to make choices about aspects of life that are important to them. By moving a resident from one room to another, the facility may be failing to meet these requirements. If the purpose of a move is to relocate within a Medicare wing or from a Medicare wing, a resident may refuse to transfer and may be entitled to a hearing.

Transfer to hospital. When a resident is transferred to a hospital, the home must give the resident and family a written notice explaining its policy on holding beds. The policy should say how long the bed will be held and how much will be charged to hold it. Facilities must readmit residents participating in Medicaid to the first available semi-private room.

Marla's father has Alzheimer's disease, and has been living at Sunset Care for three months. He had a rough time adjusting at first, but has accepted his new surroundings and resolved to make the best of them. Marla has noticed, however, that he has grown increasingly agitated in the last few weeks.

Now the Director of Nurses is on the phone to Marla, telling her that Sunset Care cannot continue to care for her father, and asking that she find a new facility for him within three days! When Marla asks why, the director says her father is wandering into other people's rooms and threatening them. The message throws Marla into a panic. She is an only child and her father is a widower. Marla has a full-time job and two small children. What should she do? What are her rights? What are her father's rights?

Sunset Care has failed to give the required thirty-days notice of discharge, and to inform Marla and her father of their right to appeal the transfer. Marla needs help from someone who knows the federal and state regulations on discharge. She can call the local or state ombudsman or seek guidance from the agency that licenses nursing homes. She can request a hearing to contest the transfer. Often, a conference or outside consultation can encourage the nursing home to reexamine its decision and find out the reason Marla's father is entering other resident's rooms. (See chapter 5 for discussion on wandering.)

- ⇒ **TIP** -- Find out how to contact your local and state Long-Term Care Ombudsman Programs and State Licensing Agencies before you need them. Contact information is in Appendix 7.

The Right to Security for Possessions

With the many losses residents endure when entering a nursing home, it would be ideal if they could have familiar room furnishings around them. Residents do have the right to bring their own things into the nursing home, as space permits. The problem, of course, is that there usually isn't much space. Personal possessions, alas, are frequently misplaced or stolen. Consequently, nursing homes advise people to leave anything of value behind with relatives or to store small items, such as jewelry, in a safe in the facility. Some nursing homes have locked drawers or cabinets in residents' rooms. Other homes are willing to remove the institutional furniture and encourage residents bring their own.

One of the most common complaints from residents and families relates to lost clothing. Was it lost in the laundry or taken by mistake? Did it simply disappear mysteriously? Missing articles don't have to be an accepted feature of nursing home life. Many nursing homes pay serious attention to reports of missing items and have specific follow-up procedures.

Those facilities with fewer cases of lost property usually have the same staff permanently assigned to the same residents. They become protective of resident's personal belongings. These facilities also involve staff in working toward residents' care goals.

⇒ **TIP** -- Take an inventory upon admission. Residents and families should keep a copy. Clothes and dentures should be appropriately marked for identification. Update the list when changes are made.

If a possession is missing:

- give the facility a written request for locating the missing possession and include an expected date for a reply;
- ask what the home's policy is for replacement of lost articles. Some homes have insurance policies to cover larger items.

⇒ **TIP** -- You may wish to extend your homeowner's insurance policy to the resident's belongings.

Your grandmother has been in Rosehips Care Center for two months. Over that period of time, two dresses, her afghan and four pairs of hosiery have been lost. When you ask staff about it, they say you must accept that these things happen in a nursing home.

The fact is that you need not accept such a situation. You should expect that staff will take responsibility for locating or replacing lost items. It would be helpful to discuss this problem in a resident or family council meeting, or both.

Keep in mind that a nursing home is part of the community and problems involving stolen items may need to involve the local police.

The Right to Raise Concerns

The problems that arise in nursing homes are frequent, varied and complex. Most concern basic care, and often stem from staffing. Short staffing and high turnover rates may result in call lights left unanswered, residents bathed sporadically, and staff too busy to help residents with meals.

Staff attitude and behavior toward residents are common sources of resident complaints. Hurried grooming services or care treatments and thoughtless or abusive staff language affect the dignity and self-worth of residents. You wouldn't put up with it from your barber or your next-door neighbor; why should that change when you move into a nursing home?

Many times staff do not realize that the language they are accustomed to using at home, that they may have grown up with, that they use with their children, sounds harsh and frightening to an older person who never used "shut up." This language is not acceptable and can be considered verbal abuse. It points out the need for staff education and training.

Verbal as well as physical abuse should be reported to the administration. Most facilities will take immediate steps to investigate and correct the situation.

Fear of Complaining

It is important to recognize and appreciate a resident's fear of retaliation. An individual who lives twenty-four hours a day totally dependent on caregivers may feel that challenging or offending those caregivers, or making repeated requests, may make them even less likely to respond to his needs. As one family member remarked: "I felt the same way when my children were in school. I was afraid to complain to the teacher for fear he would take it out on my son."

It's true there are instances where residents suffer indignities because they or their families have expressed their concerns. Indeed, they may be labeled as "chronic complainers." After all, staff may find it easier to label someone than to take the time to address that person's special needs.

But fear of complaining is often unjustified. Indeed, raising concerns is essential to receiving better care. Residents, family members and ombudsmen agree that being assertive and identifying problems usually brings good results. Becoming directly involved in care planning, as discussed in chapter 3, is one of the best ways for you and your relative to ensure rights are respected.

⇒ **TIP** -- It's not what you say, it's how you say it! Expressing your concerns in a friendly-but-firm assertive manner will usually be much more effective than making aggressive demands.

Facility Responsibility

Every nursing home has a responsibility to make sure that residents and staff are aware of residents' rights. This entails assisting residents in raising concerns individually, in resident councils, or in care planning meetings. The facility is required to respond promptly to these concerns.

When Betty visits her mother, she often finds her sitting in urine or stool. Betty has taken her concerns to the aides and the charge nurses who frequently tell her that they just don't have enough staff that day. She also has gone to the administrator several times. On the last occasion, Betty was told that, if she is dissatisfied, she "may wish to find another nursing home."

This response signifies the facility's unwillingness to address the problem. It may be time to call for outside help. Chapter 7 offers specific ideas and resources for solving such problems.

Step Up, Speak Up, and Advocate for Good Care

- Know that *privacy* means that curtains must be drawn when care is given!
- Know that *participation in care planning* means a serious consideration of resident views and concerns!
- Know that *being treated with dignity* means being taken seriously and not being labeled a "complainer!"
- Know that *your relative's rights regarding transfers* mean that she can't be asked to leave because you or she raised concerns!
- Know that *your relative's right to choices* means that she can decide whether to play Bingo or take a nap!

This chapter has touched on just a few key aspects of nursing home residents' rights and how to seek help in exercising those rights. Residents' rights is a theme that steers virtually every aspect of nursing home care, from admission to discharge. The most critical thing to remember is that *residents retain their basic right to be in control of their lives*. Living in a nursing home does not take away that right!

In the next chapter, "Assessment and Care Planning: Receiving Individualized Care," you will learn more specifics about how you and your relative can have an active role in planning care and treatment. Assessment and care planning are concrete ways a resident can exercise the right to participation and maintain some choice and control. Read on for lots of ideas about making rights a daily reality!

- All laws are subject to change. Regardless of any changes in the federal law discussed in this chapter, these standards are supported in state laws as well as professional codes of conduct. They are good practice! They represent good care! As a family member you have every right to ask for and expect these practices for your relative.—

Copies of ***Nursing Homes: getting good care there*** may be obtained from NCCNHR at www.nccnhr.org or 202.332.2275

STRENGTHENING RESIDENTS' RIGHTS

There are several basic reasons why many residents are unable to address problems on their own.

- Many residents are unaware of their rights or are unaware of what facilities are required to do.
- Even if they know their rights, many residents are unable to work through the complexities of a problem-solving process because of physical and/or mental limitations or because of a lack of support.
- The process of solving a problem may seem overwhelming.
- Institutional factors, such as isolation, lack of power, and resistance to change can make it difficult for a resident to resolve a problem without assistance.

Three measures that are especially useful in helping residents exercise their rights are discussed in this section: empowering the individual resident, working with resident councils, and working with family councils. The tables on the following pages can be used with each of these groups to help explain some common impediments to exercising residents' rights and to find ways to overcome them.

Table 1 lists a number of the reasons residents are reluctant to assert their rights on their own behalf.

Table 2 lists other obstacles that further impede implementation of residents' rights.

Table 3 lists a number of measures that nursing homes can take to promote and strengthen residents' rights.

A discussion of the role of the ombudsman in empowering individuals and in assisting with resident and family councils follows the three tables. Keep reading for inspiration and very useful tools!

TABLE 1

**REASONS RESIDENTS DO NOT
ROUTINELY EXERCISE THEIR RIGHTS**

1. Residents are intimidated by the idea of appearing in any way to criticize the nursing home.
2. Most residents do not know that they have specified rights and do not know what their rights are in a nursing home.
3. Most residents do not even think about their problems and concerns in any context related to their “rights.”
4. Residents have very few opportunities to exercise control over their lives or to have intellectual discussions.
5. Residents have few relationships in which to practice interactive or assertiveness skills or negotiate their rights.
6. Even residents who are aware of their rights must choose their “battles” and often put up with daily violations of their individuality and dignity because: (a) it requires too much strength to challenge each encounter; (b) they are easily labeled troublemakers; (c) they are dependent for their basic care on those very people and, therefore, hesitant to criticize, and, often, (d) they experience a sense of defeatism.
7. Most residents have come to accept that many of their rights are violated as a part of the daily nursing home routine and, therefore, would never articulate them as problems about which anything can be done.
8. Many residents face a tension between their desire for independence and their need for assistance.
9. Residents often feel more comfortable championing another's problem than asking for help for themselves.
10. Residents face physical, emotional, psychological, social, and/or mental disabilities that make it difficult for them to voice their concerns.
11. Residents' autonomy is undermined from the start by the very fact that most residents would rather not be in a nursing home; many did not have much of a role or choice in the decision to be there, and most have no other options.

Source: National Citizens' Coalition for Nursing Home Reform, Nursing Home Residents' Rights Project, 1828 L Street, NW, Suite 801, Washington, DC 20036

TABLE 2

OBSTACLES TO IMPLEMENTING RESIDENTS' RIGHTS

1. Many residents do not know about or understand their rights.
2. Most residents feel that asserting rights is a negative thing to do.
3. To exercise their rights, residents need the physical care necessary to promote self-reliance and renewed strength, such as: appetizing food to suit their nutritional needs, rehabilitative and restorative therapy, meaningful activities, and freedom from over-medication and over-restraint.
4. Residents who do assert their rights often face tremendous resistance from every level of staff, which discourages them and makes it nearly impossible for them to succeed.
5. Most residents do not have many social supports inside or outside the home to encourage or assist them to live to their fullest.
6. Most resident councils do not receive the leadership development they need to function effectively.
7. Many resident councils meet resistance from staff when they voice concerns.
8. Few families understand residents' rights or know how to empower their relatives to maintain self-determination.
9. Most nursing homes are run in a very regimented, institutional fashion, which leaves little room for individuality, free expression, personal autonomy, or choice.
10. Most nursing homes provide few opportunities to foster relationships.
11. Many staff do not know about nor understand residents' rights.
12. Very few supervisory and managerial personnel understand residents' rights.
13. Sometimes staff feel threatened by "residents' rights."
14. Staff is often poorly trained in residents' rights.
15. Often, staff is not treated in a manner respectful of their own rights.
16. Short staffing prevents staff from taking the time necessary to treat residents respectfully in routine care and treatment.
17. Staff is used to "caring for" residents and do not know how to empower and enable residents to care for themselves.
18. It takes longer to help someone do something for himself/herself than to do it for him/her.
19. Many staff perceive residents' concerns and recommendations as too bothersome and another demand on an already burdensome schedule.
20. Most staff and others see residents' disabilities instead of their abilities.

Source: National Citizens' Coalition for Nursing Home Reform, Nursing Home Residents' Rights Project, 1828 L Street, NW, Suite 801, Washington, DC 20036

From: *Equipping Long-Term Care Ombudsmen for Effective Advocacy: A Basic Curriculum*, module on **Residents' Rights**. Developed by Sara S. Hunt for the National Ombudsman Resource Center, 2005. Available from the National Ombudsman Resource Center, www.ltombudsman.org; 202.332.2275.

TABLE 3

**HOW FACILITIES CAN PROMOTE AND
IMPLEMENT RESIDENTS' RIGHTS**

- Educate residents and their families about their rights
- Educate and sensitize every level of staff about residents' rights.
- Incorporate resident participation and self-determination into every aspect of nursing home services (e.g., resident advisory committees for food services, activities, housekeeping)
 - Provide more support to workers, including sufficient staffing ratios, training, better supervision, dignified working conditions, and increased salaries and benefits.
 - Orient nursing assistants to the residents they will work with, and promote relationship building between staff and aides
 - Utilize the information and wisdom of residents and their representatives to help develop and conduct training programs for staff.
 - Help staff, residents, and families overcome the tension between dependence and empowerment. Residents need assistance, but the help they receive should increase their ability to help themselves.
 - Establish a grievance committee comprised of residents, family, staff, and administration.
 - Encourage and promote an open exchange of ideas, recommendations, and concerns throughout the facility among residents, families, staff, and administration.
 - Build more private rooms for individual residents and public rooms for private use by residents as needed.
 - Promote a sense of community within the nursing home. For example, organize activities for each wing and each floor or design activities that promote interaction and intellectual and emotional stimulation.

Source: National Citizens' Coalition for Nursing Home Reform, Nursing Home Residents' Rights Project, 1828 L Street, NW, Suite 801, Washington, DC 20036

STORIES RIGHTS

Long-term care ombudsmen, activities professionals, and others submitted the following stories and others related to residents exercising choice.

When the ombudsman received a copy of a discharge notice for Mr. Lee, she went to the nursing home to visit him and offer her assistance. Mr. L, age 52, was indigent and receiving no benefits, so his nursing home bill wasn't being paid. Although a disability benefits application had apparently been filed, its status was unclear. Mr. L, who suffers from lung cancer, informed the ombudsman that his chemotherapy and physical therapy had been discontinued, even though he felt he had been making progress. He also said he was in severe pain. The ombudsman reviewed his medical records and found that his pain medication prescription had expired, but no one had called his physician to renew the prescription. She also discovered that Mr. L's mail was being delivered to the wrong address, so any information regarding the disability application and doctor's appointments would not have been received. The ombudsman assisted the resident in getting his disability application resubmitted, getting his mail properly delivered, and advocating for the facility to renew the pain prescription and other needed treatment. Today Mr. L receives disability benefits, so his care is being paid for, and he is getting the care he needs. He tells the ombudsman that, with therapy, he hopes to one day move back into the community.

Submitted by: Becky Kurtz, Georgia State Long-Term Care Ombudsman

Ms. M, 28 years old, had an interest in Mr. T, a young man who had asked her out on a date. For most young women this would have been happy news. But Ms. M lives in a nursing facility that prohibited her from going on a date, claiming this was Ms. M's family's wish, despite the fact that Ms. M's physical disabilities had not limited her capacity to make her own decisions.

Ms. M contacted the ombudsman requested a meeting with the ombudsman, facility staff, Ms. M and Mr. T. The group met and worked out an agreement that made the facility comfortable that it was meeting its obligations to care for Ms. M, but still permitted Ms. M to leave the facility with Mr. T.

Submitted by: Becky Kurtz, Georgia State Long-Term Care Ombudsman

We had a lady in our facility, who had no family and very few friends. As an activity professional, I was looking for more information on this very sweet lady. There were times when she would become very upset and then would exhibit behaviors that interfered with staff's ability to provide care for her.

One day neighbors came in to visit her and I asked if I could talk to them about interests of this resident. I was told that she was a very quiet person and had very few interests, other than music. I asked if they knew what kind and was told it was yodeling. I went to the library and found some of this kind of music and brought it back to the facility.

When, I played it for her, she started to follow the music and began to yodel. The smile that came on her face was worth a million dollars. We found that when she was becoming upset, if this music was played, she became relaxed and started to yodel right along with the music and would smile and say, "What would you like for me to do?" Staff learned to start her day by playing this kind of music for her in the morning, when she got up.

Submitted by: Bonnie Ruggles-Ruechel BS, ACC

In our facility, there was a resident who had brain cancer. He was admitted and placed in the dementia unit with Alzheimer's residents. The residents in this unit were all over 75 years of age and here he was only 40 years of age.

Soon, he didn't want anything to do with anyone and resisted care. In doing his assessment, the activity director found that he was a veteran. She contacted the VFW, of which he was a member. They started to come to the facility and took the resident to their meetings and even made him, the Grand Marshall of the parade that was held in Prescott every year.

The activity director also, collected some of his wartime items that were very precious to him. These items were placed in a shadow box with a Plexiglas cover and hung on the wall for the resident to enjoy. The items in the shadow box were changed periodically. The items being placed in a shadow box, with a flex-a-glass cover, helped keep the items safe, as no one would be able to take them or so that they wouldn't get misplaced.

This resident died in this unit, but his last days were reliving his memories he had collected during his life in the army.

Submitted by: Bonnie Ruggles-Ruechel BS, ACC

Ms. A had made great progress during her year in the nursing home – her broken hip had healed, she was mobile, and her chronic conditions were under control. Her physician felt she would do fine at home, and in-home services had already been arranged by the facility.

The only obstacle was her family. They claimed that Ms. A's house was in disrepair and uninhabitable. One family member claimed he had guardianship and refused to agree to her discharge. However, upon investigation, no guardianship had ever existed.

When the ombudsman met with Ms. A, her family, and facility staff, she suggested that the resident at least be able to see the condition of the home. While the family at first protested – and threatened to report her for trespassing if she returned to the property -- they eventually relented. Ms. A visited her home and found it to be in good shape. Today, Ms. A happily reports that she is able to receive the services she needs in her own home.

Submitted by: Becky Kurtz, Georgia State Long-Term Care Ombudsman

Mrs. G used to love to get her hair washed, but at the nursing home she became combative during a shampoo. Her family informed the ombudsman that they thought the problem was the beauty parlor chair. The ombudsman investigated and found that the chair was in bad repair, not stable or attached to the floor, and gave an abrupt and startling jerk as it was lowered toward the sink. Water would cascade down a resident's back as she was being shampooed. After the ombudsman discussed with the facility her findings about the discomfort and potential danger of the chair – and the fact that having their hair washed and set is a favorite activity for many residents – the facility replaced the chair immediately. Today residents can experience the highlight of their week in comfort and without soaking their clothing.

Submitted by: Becky Kurtz, Georgia State Long-Term Care Ombudsman

Mrs. M, 94, had been using “briefs” provided by the nursing home for occasional incontinence accidents until she was informed that the briefs were too expensive and she had to use “pads” instead. Mrs. M found that – unlike her independent use of briefs – she needed assistance from staff and had to wait for the pads to be changed. She told the ombudsman that she was very distressed about the indignity of being changed by staff and the odor. The ombudsman advocated for the home to provide Mrs. M with briefs, explaining that the money saved was actually costing more in staff time. The home's administration agreed that Mrs. M's dignity and independence were more important than saving a few dollars on briefs. Today, Mrs. M is proud to have her hygiene – as well as her dignity and independence – restored.

Submitted by: Becky Kurtz, Georgia State Long-Term Care Ombudsman

Nursing home facilities in Weld County do an exceptional job of caring for their residents. Programs such as the Caring Angel and Guardian Angles are a few examples of how facilities welcome and care for their residents. These programs are designed to assign staff to different resident rooms. If a new resident is moved into a room assigned to them, it is that staff member's job to show the new resident around. They are there to welcome the new resident and be there in times of discomfort. The Guardian and Caring Angels have a duty to touch base with the residents at least once a week. This promotes an open relationship and makes the residents feel like somebody actually cares about them. Meeting

with the same person every week can build a meaning and trustful relationship. Residents have a person who they can turn to when complications or complaints arise. There are lots of opportunities for residents to make comfortable and caring relationships.

Another item in place to promote choice and have close ties is having neighborhood meetings, which are resident councils. This is more conducive to meet the needs and wants of residents. Facilities are beginning to realize that each neighborhood, wing, or floor is unique and all have different needs. Having a smaller and more focused group allows more problems and ideas to be ironed out.

Facilities in Weld County offer a multitude of activities to encourage choice, promote independence, and empower residents. Everything from one on ones to huge group outings is offered. Just to name a few activities; exercising, educational outings, memory games, sensory activities, reminiscing, pet and music therapy, dancing, baking, crafts, socials, gardening and of course the game that Human Kind will never out grow Bingo. The community also plays a big role with intergenerational activities. Many facilities recruit elementary schools for fun activities for seniors and children. One of the most important activities is a family social. Many facilities have socials for residents and family at least once a month and for holidays. For people who are feeling depressed or lonely a special activity offered is a small cooking group. This activity is for residents who need a little extra attention, to give them a sense of purpose.

Some long-term care facilities are not able to afford expenses for big activities. The activity directors in these facilities do an amazing job of finding cheaper or free events. The process of finding activities for seniors on limited income can be tedious and difficult. The dedication these directors give is truly amazing.

I think nursing facilities of Weld County promotes choice and empowers residents in many ways. I believe they care about their resident needs and want to have their residents be as happy as possible. I think their Guardian and Caring Angel program is a great way to build healthy relationships.

When asked about how a facility would like to see the problem of loneliness handled, one activity director said, "Care, compassion, and spending time with each person."

Compassion combined with care can equate to a great running facility. The residents are to be cared for and with compassion from others their stay can be an enjoyable one. The staff that cares for our elders in Weld County is truly a blessing. The people who have the desire and heart to help people in need deserve a little more credit. But in essence they are happy doing their job with out any recognition.

Submitted by: Rachel, Volunteer Ombudsman, Weld County Facilities

Previous administrator requested us to assist in the locating of a birth certificate for a resident contacted ombudsman office. Resident had been admitted after suffering a diabetic stroke; nursing home was advised that she had been in process of securing social security benefits. They were advised that there was a discrepancy in her birthplace so her benefits would not be released. She had been checked in by a "common law husband" who now wanted nothing to do with her. It was said that he had also alienated her son from her by revealing he had been adopted. Common law husband mislead ombudsman staff as well as nursing home staff for sometime which made efforts to assist her more difficult. Nursing home issued an eviction notice, however, common law husband refused to accept it, getting his landlord to advise the nursing home that the resident would not be allowed to live there.

Lower Rio Grande Valley Area Agency on Aging staff decided to work diligently for this resident, who had absolutely no one on her side. We contacted and worked with Adult Protective Services, Health and Human Services, Dept. of Aging and Disability Services, Texas Legal Services, Social Security Administration, Brownsville Independent School District, Raymondville Independent School District, Brownsville Catholic Diocese, Cameron County Clerks Office, Cameron County Voters Registration, previous employers, and one long lost relative.

Through the help of a Legal Services attorney, we personally interviewed the client, who insisted she was born in a "colonia" in Brownsville, "Los Coyotes", which no longer exists. Since we were not able to locate her birth certificate, we asked her parents' names. The County Clerk performed searches free of charge. We were able to locate her father's birth certificate, which meant that she had at the very least, dual citizenship. Also located a stepbrother, who verified her father's birth date.

Mr. S prepared an affidavit in Spanish for stepbrother, who traveled to Brownsville from Mexico, to sign it as well as visit his stepsister, whom he had not seen for years. That affidavit was notarized and sent overnight to Mr. S in Austin. Mr. S has worked with Social Security Administration as well as Bureau of Vital Statistics in the hope to secure her a delayed birth certificate. With this, she will be able to remain in the nursing home, eventually receive therapy and perhaps even return to living outside the facility.

Submitted By: Debra Lachico, Managing Local Ombudsman, Texas