

Good CARE in Nursing Homes: Everyone's Basic Right



Good Care in Nursing Homes: Everyone's Basic Right



*Protecting and improving the quality of care and life
for residents in Arkansas nursing homes*

By Arkansas Advocates for Nursing Home Residents (AANHR)

This book has been written by

Arkansas Advocates for Nursing Home Residents (AANHR)

P. O. Box 22421, Little Rock, AR 72221-2421

AANHR'S Mission:

To protect and improve the quality of care and life for residents in Arkansas nursing homes.

About AANHR:

AANHR was founded in 1995 by individuals concerned about the well-being of nursing home residents. The membership includes family members and friends of nursing home residents, community supporters, nurses, physicians, other health care workers, service agency representatives, and attorneys.

Since our formation in 1995, we have striven to educate ourselves and others about how to get good care in a nursing home. This book, a compilation of what we have learned through teachers and experience, describes what to look for to ensure good care for your loved ones in nursing homes. Knowledge is power, and we're happy to offer the material in book form.

For more information:

E-mail: infor@aanhr.org

Website: www.aanhr.org

Phone: (501) 450-9619

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GOOD CARE



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AANHR Membership Form

Arkansas Advocates for Nursing Home Residents

Membership is open to everyone except persons affiliated with or representing the nursing home industry and its regulatory agencies.

- *I would like to be on the AANHR mailing list.*
- *I would like to become a member of AANHR.
(Individual - \$15, Corporate & Family - \$20, Student
or CNA- \$4. Contributions are used to cover postage,
printing handouts, telephone, and maintenance of the
AANHR website.)*
- *I would like to donate volunteer time.*

Name: _____

Phone: _____

Address: _____

City: _____

State/Zip _____

***Make check payable to AANHR and send to P. O. Box 2241,
Little Rock, AR 72221***

HELPFUL/IMPORTANT NUMBERS

Report Complaints about care and suspected abuse to:

Toll Free 1-800-LTC-4887

Office of Long Term Care (OLTC)

P. O. Box 8059, Slot 404

Little Rock, AR 72203-8059

OLTC WEBSITE:

[HTTP://WWW.MEDICAID.STATE.AR.US/Internet](http://www.MEDICAID.STATE.AR.US/Internet)

Solution/General/units/oltc/index.aspx

Report suspected abuse to:

Office of Long Term Care (OLTC)

Toll Free 1-800-LTC-4887

Attorney General

Toll Free 1-866-810-0016

For Complaints and answers to questions you may also contact:

Your local **Ombudsman**, whose number should be posted in the nursing home. You may also call your local Area Agency On Aging to secure **the name and phone number** of the Ombudsman.

Arkansas Advocates for Nursing Home Residents

www.aanhr.org

info@aanhr.org

1-501-450-9619

National Citizens' Coalition for Nursing Home Reform

Washington DC

www.nccnhr.org

1-202-332-2275

For legal advice: Arkansas Trial Lawyers Association

1-800-442-2852

TABLE OF CONTENTS

GOOD CARE: EVERYONE'S BASIC RIGHT...PAGE 1

THE ADMISSION PROCESS.....PAGE 3

WHAT CONSTITUTES GOOD CARE?.....PAGE 4

OTHER THINGS YOU NEED TO KNOW.....PAGE 12

WHAT TO DO WHEN A PROBLEM ARISES...PAGE 13

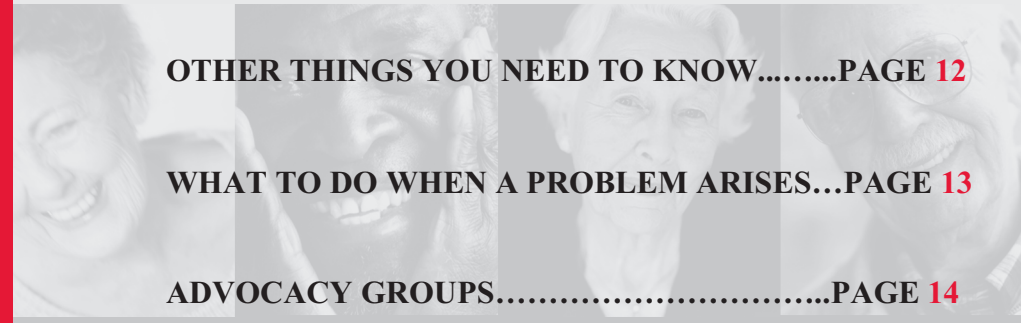
ADVOCACY GROUPS.....PAGE 14

THE FAMILY COUNCIL.....PAGE 15

END OF LIFE ISSUES.....PAGE 17

HELPFUL/IMPORTANT NUMBERS.....PAGE 19

AANHR MEMBERSHIP FORM.....PAGE 20



Caring For Your Nursing Home Resident

GOOD CARE: EVERYONE'S BASIC RIGHT

Persons do not give up their basic rights just because they move into a nursing home. They have the same basic rights that they enjoyed in their own homes, plus additional rights given by federal and state law. (Arkansas code 20-10-1003 and 20-10-1204, and 42 CFR part 483.10(b)(4)) These include:

- * the right to good care and safety
- * the right to privacy and to be treated with dignity and respect
- * the right to participate in planning one's own care with attention given to personal preferences
- * the right to meet with or have visits from persons of one's own choosing
- * the right to complain without fear of retaliation

For a more complete listing see *A Guide to Residents' Rights*.

Although the law requires that nursing home residents receive the best possible care, that does not mean it will automatically happen. Like any right, everyone involved must be aware of that right and be prepared to protect and defend it. Residents who are dependent upon the nursing home staff for care are at

* **Financial Durable Power of Attorney** - in which a person is appointed to make business and financial decisions for the resident. This person is not authorized to make health decisions.

* **Health Care Durable Power of Attorney** - which names the person to make decisions about health care and treatment.

Appointment of such a person may avoid later quarrels between family members who may disagree about treatment.

Advance Directives must be in writing, signed by the maker, and witnessed by two other adults. Forms prepared by the Health Law section of the Arkansas Bar Association are available at <http://www.arkbar.com> or from any attorney.

Consult "The Family Council Guide" provided by the Office of Long Term Care and on their website (see "Helpful/Important Numbers"). The nursing home must provide a place for the Family Council to meet but must otherwise not interfere with Family Council activities. To allow open discussion of problems, staff are not to attend Family Council meetings unless specifically invited.

END OF LIFE ISSUES

During the admission to a nursing home, your loved one will be asked if he/she has an Advance Directive, a legal document which will guide the doctor and the nursing home regarding treatment if your resident becomes unable to express his or her own wishes. If a resident does not have an Advance Directive and is or becomes unable to make their own decisions, someone else will make those decisions and it may not be what the individual would have wished. It is important to understand that these documents take effect *only when the resident is unable to make or express his or her own wishes* and that they can be revoked or changed at any time.

There are at least three important kinds of Advance Directives.

* A **Living Will** tells family members and medical professionals to what extent special means should or should not be used when a person becomes incurably ill or permanently unconscious. Such a statement can relieve family members of the burden and stress of trying to guess at a very emotional time what their loved one might want.

a disadvantage and may be powerless. This is where you, as a loving and concerned friend or relative, with permission from your resident, can become his or her advocate. To do this you need to know what good care looks like and what your rights are. We hasten to add that to be effective you must always be polite, self-controlled and considerate of everyone's needs and rights, not just your resident's, at all times.

Family members or friends who have been designated by a resident to speak for them, have rights also. These include:

- * to be included in planning the care of your loved one
- * to oversee the care and to communicate your concerns to staff members without fear of reprisal against your resident
- * to have access to information, including:
 - Resident's rights
 - The report of the most recent inspection of the nursing home by the Office of Long Term Care, including any Plan of Correction currently in effect
 - Who is caring for your loved one. Names of all direct care workers working at the present time must be posted on each hall or wing of the nursing home. Staff on duty must also wear nametags for easy identification.
 - The name and contact information for the nursing home ombudsman (see page 13).

- the right to meet with other family members and form a Family Council (see pages 15-17).

There has been much publicity in recent years about monitoring nursing home care with the use of surveillance cameras. At the present time **there is no law prohibiting the placement of a surveillance camera.**

THE ADMISSION PROCESS

Care in a nursing home begins at admission. The admission process is extremely confusing and usually takes place under extreme emotional distress. The paperwork is overwhelming! Remember that the admission process is a **legal transaction**. If at all possible study the admission forms before admission and seek legal advice about anything that you do not understand. Two areas to be aware of:

*** Arbitration Clause** - Be aware that some nursing homes include in their contracts a Binding Arbitration Clause. This is a statement that you will agree to take all disputes to an arbitrator. The arbitrator's ruling is final. There is no appeal. By signing such a contract you **lose the right to take legal action**. It is perfectly legal to cross out such a clause and a nursing home cannot legally deny admission to persons with Medicare or Medicaid who refuse to sign an arbitration clause.

***Liability Insurance** - Some nursing homes have dropped liability insurance coverage, thinking this shields them from potential law suits. You may wish to ask for their Certificates of Insurance, which will tell you of their coverage and limits.

One family member who is part of an active and successful family council says, "Because I am a member of a group with a common denominator, I have felt a sense of belonging and security. The Family Council meets monthly to plan projects, and to talk about how things are going at the nursing home. This grants us all the opportunity to gain support from each other, and to possess the power to suggest and/or make changes....Family members are free to voice concerns to the Council president, which she delivers to the administration. This keeps the family anonymous and blocks any possible repercussions. This enables the administration, staff, residents and families to successfully address many problems because a comfortable open dialogue is encouraged. I have observed everyone working together to sort out what suggestions are reasonable, what the past has been, and what changes may be possible....Some of the family council members are at the home daily, and can help assess loved ones whose family may not be able to visit as often. Unfortunately I cannot see our son as often as I would like because we live 130 miles away. I have been assured that someone, in addition to the staff, will interact with our son on a frequent basis, and will communicate with the family council president if there is a concern. This is a tremendous safety net."

Every nursing facility should have an active Family Council. If there is not a Family Council to represent residents at your facility, consider starting one yourself. Call a meeting. If a few interested people come and elect a president, and meet periodically, you have your Family Council!

Persons who are concerned about care in nursing homes have organized into advocacy groups to work at local, state, and local levels to inform family members about issues that affect nursing home care, to research and provide information about good care practices, to promote the proper enforcement of existing regulations, to be aware of pending legislation that will affect nursing home residents and to promote legislation that will improve care.

In Arkansas, that group is **Arkansas Advocates for Nursing Home Residents**. This is a totally volunteer group. They may be contacted by telephone at 501-450-9619 or on the Internet at www.aanhr.org or by e-mail at info@aanhr.org.

The **National Citizens' Coalition for Nursing Home Reform** is a national membership organization for nursing home residents, families, long-term care ombudsmen, and citizen advocacy groups. It is headquartered in Washington DC. Check its website at www.nccnhr.org or telephone at 202-332-2275.

THE FAMILY COUNCIL

An often overlooked but potentially powerful force in seeing that good care is provided in a nursing facility is a Family Council. A family council is made up of family members and friends of residents who work together to protect and improve the quality of life for the residents in the home and to give families a voice in the decisions that affect them. It also provides a forum for family members to be heard about concerns and to obtain information about changes and issues affecting the nursing home.

WHAT CONSTITUTES GOOD CARE?

Good care can reduce pain and prevent, or slow down, the loss of function that goes with aging or disease. With good care, many nursing home residents can maintain or even improve their ability to get around and to take care of themselves. What do you need to look for to ensure good care?

*** Adequate staffing.**

Numerous studies have shown that the first and most reliable indication of good care is enough direct care staff. Families naturally sympathize with overworked nursing assistants (CNAs) who have too many residents to care for. You should not, however, lower your expectations for good care. **Nursing home residents have a right to good care whether or not it is difficult to find or keep workers. Nursing homes must maintain enough staff to meet the needs of residents.** They can attract good workers by improving wages and benefits. They can keep good staff by providing nursing assistants with good supervision, adequate training, sufficient supplies, and by treating them as important members of the care team.

Law requires that the names of all direct care staff that are currently on duty must be posted on each wing or hall of the nursing home. The number of residents on that unit must also be posted so you can figure how many residents each CNA is assigned.

Watch to see if call lights are answered promptly or if residents seem to be ignored by staff.

* Your loved one's Plan of Care.

All nursing homes are required by law to develop an individualized plan of care for each resident, tailored to meet the needs of that particular person. The plan of care contains all the promised care the facility says it will provide to your loved one. This must be written shortly after admission and it must be reviewed at least every three months, or more often if there is a change in his or her condition.

Family members have the right be included in these planning meetings. Insist upon that right. If necessary, the meeting date and time should be adjusted to make your attendance possible. Invite the Ombudsman and/or a relative or friend to be with you if you wish.

You should be provided a copy of the Care Plan. Observe it closely to see that what was planned is what is being given to your resident. If the plan of care does not meet their needs, talk to the Director of Nursing to make sure that changes are made to meet those needs. Ask the CNAs if they have seen the care plan or have been instructed about it so they know what care is needed. It is not unusual for CNAs to be excluded from the care planning process and therefore to be clueless about the special needs of your loved one.

The Care Planning process, of course, cannot provide all that caregivers need to know about your loved one. Tell staff about your resident's personal preferences and special needs; however, do so in a positive, helpful manner. On very important matters, take the issue to the next level of authority.

a nursing home. His or her name and phone number is, by law, supposed to be prominently displayed in each facility or may be contacted through the Area Agency on Aging in your area. An ombudsman can be a valuable influence in solving disputes but they have no authority over the nursing home.

The next step may be to file a complaint with the **Office of Long Term Care**, the state agency responsible for enforcing rules and regulations governing nursing homes. The Office of Long Term Care investigates complaints against facilities as well as allegations of abuse or neglect of residents, theft of residents' property, and poor quality of resident care. Investigations are confidential, and you do not have to give your name when you file a complaint. If you choose to give your name, you will be informed when the investigation is completed. You can file a complaint by telephone, fax, e-mail, or letter. (See resources in back of book) but be aware that an investigation and follow-up may take some time.

Other sources of assistance may be the **State Attorney General** 1-866-810-0016 or you may wish to contact a **private attorney**. To find one familiar with nursing home matters you can contact the Arkansas Association of Trial Lawyers of America (ATLA) 1-800-442-2852.

ADVOCACY GROUPS

It is possible to affect the care of not only your own loved one but all nursing home residents.

WHAT TO DO WHEN A PROBLEM ARISES

A minor problem regarding care may be solved by a friendly visit with the **CNA** who provides the hands-on care for your family member, and indeed she is the one who can tell you about any changes in your loved one. However, remember that the CNA probably has no authority to change procedures. Next in command is the **Charge Nurse** and this is the person who gives out medications and directly supervises the care given by the CNAs. She should be contacted when there are questions about whether the plan of care is being carried out or about medication problems. The **Director of Nursing (DON)** has the ultimate responsibility for all nursing care in the nursing home and for the nursing staff to provide it. The DON should be notified about any serious problem having to do with the health of a resident or with nursing care. The **Administrator** of the facility sets policies, controls the budget, and has control over the day-to-day functioning of the nursing home. Most administrators want to be notified about problems or complaints and only they may have the power to make changes. Each nursing home also employs a **Social Services Director** (or Social Worker) who can be of assistance for problems regarding personality conflicts with roommates or other residents and other day-to-day general living adjustments, and finances.

If you are not satisfied with the results after going through the "chain of command" at the nursing home, another resource is the local **Long Term Care Ombudsman**. It is the job of the ombudsman to advocate on behalf of residents in conflicts with

This could be the Charge nurse, Director of Nursing or Administrator. (See section on "What to do When a Problem Arises" page 13.)

*** Adequate food and water**

Making sure that your family member is drinking enough water and eating well is so basic that it is an area often overlooked by families. Nutritious food and enough fluid intake is vital to preventing life-threatening illnesses such as urinary tract infections, kidney failure, skin breakdown that can lead to bedsores, even mental confusion which may be misdiagnosed as Alzheimer's Disease.

*** Dehydration**

Dehydration is a common cause of death in nursing home residents. Residents with severe physical disability may be unable to reach a drink or unable to lift a heavy pitcher of water. Many who are confused may forget to drink. Busy CNAs may forget to offer water on a regular basis, so you need to urge your loved one to take a drink every time you visit.

To check for dehydration, look for symptoms such as dryness in the mouth and lips, reduced urine, decrease in body temperature, and acute weight loss. Also look for skin tone by gently pinching the skin on the forehead or breastbone to see if the skin sticks together and leaves a ridge, also symptomatic of dehydration. If you suspect there is a problem, ask the doctor to order blood tests that determine dehydration and malnutrition.

***Severe Weight Loss**

Severe weight loss should always raise questions about care. Don't rely on staff reports of how well your family member is eating. Visit at mealtimes and observe the quality of the food and how well residents are helped. How many CNAs are available and *how* are they assisting residents? How many residents is each CNA feeding? Are residents rushed through the meal? Are residents leaning back in an effort to avoid being fed too fast?

If your family member is fed in bed, watch to see if they are positioned to be able to eat comfortably and observe how long the tray sits before assistance arrives. Judge weight loss by observation of the upper arms or lower legs, as the loss will be apparent there before it will in the abdomen.

*** Hygiene and Personal Care**

Dental hygiene may be the most neglected aspect of care of persons who cannot care for themselves, yet it is very important not only for comfort and the ability to enjoy food, but in preventing infection and disease. This is true whether the resident has his own teeth, has dentures, or has no teeth. It is especially important for persons who have feeding tubes or do not have normal intake of food or liquids.

Of course you want your loved one to be clean and nicely dressed. There should be no odor or scaling skin. Persons who are incontinent should be washed carefully after each episode. Bath time is frequently a source of embarrassment and great

OTHER THINGS YOU NEED TO KNOW**Your Resident's Physician**

Every nursing home resident has the right to choose and be served by his or her personal physician (with the permission of the doctor – some physicians choose not to make nursing home visits). It is the resident's personal physician who prescribes the resident's diet, medications, therapies, and all aspects of care, not the nursing home nor the nursing home's medical director. The nursing home staff may provide information and data to the physician, but the personal physician makes the decisions for that resident. It is very important that you discuss any questions, concerns, and suggestions you have about your resident's condition and the overall plan of care with his own physician.

***Medications**

The resident has the right to be served by the pharmacy of his choice, provided that the pharmacy can supply medications in the form needed by the nursing home (in unit-dose packaging, for example).

Keep a list of every medication your resident is taking. Determine its purpose, why it was prescribed, and if it is being given as ordered. Be aware that medications can have unintended side effects or cause unexpected interactions with other drugs, so whenever a new medication is given observe your loved one carefully for a period of time and immediately report new symptoms.

one in danger. Good nursing homes find alternatives to restraints. This means observing residents and talking to family members to find out **why** residents wander, fall, or become agitated. This may mean providing a safe place to wander, awareness of non-verbal signals for the need to toilet, careful monitoring of medications that may cause dizziness or unsteadiness, or a change in routine to avoid over-stimulation.

Not all restraints are physical. **Chemical restraints** are drugs used to control behavior rather than to treat their medical condition. These drugs often have serious side effects. If your loved one is agitated or has other symptoms that staff want to control with drugs, insist that they first try to find out and alleviate what is causing the problem. Rule out boredom, fatigue, hunger or thirst, need to go to the bathroom, pain or infection, before resorting to drugs.

* Abuse

Abuse can happen in nursing homes. Sometimes residents are hurt physically. Sometimes they are hurt psychologically or frightened by threats or other things said to them. Abuse may come from other residents as well as from staff persons. **Do not accept any behavior toward your loved one that you believe is abusive, including rough treatment or unkind words.** Any abuse should be reported immediately to the Office of Long Term Care. 1-800-582-4887 (in Pulaski County: 682-8425).

discomfort - even fear - if the person giving the bath is not very attuned to the resident's feelings. You will want to check to see how often and **how** the bath or shower is given. Pay attention also to the care of nails, which should never be allowed to grow over or dig into the end of fingers or toes. The services of a podiatrist (foot doctor) may be required.

*Positioning and Exercise

Positioning and exercise are an important aspect of care, especially for persons whose mobility is impaired. Correct body alignment, while sitting or in bed, is important for proper body functioning as well as comfort. Furthermore, if not moved regularly, muscles tend to contract and become rigid, forming contractures (frozen joints) and further deformity. It is important that nursing home residents be encouraged to move independently as much as possible and that the body be given full range of motion exercises and be repositioned for persons who cannot do this themselves.

If your family member is immobilized in bed or sits for long periods of time, he is at risk for **bedsores** (sometimes called pressure sores or decubitus ulcers). Bedsores can be prevented or successfully treated if caught early, but frequently lead to death from infection if allowed to develop.

Someone from the family should regularly check the pressure points of heels, elbows, ears, and especially buttocks, which are areas where the weight of the body tends to exert enough pressure to cut off blood flow to skin and underlying tissues. Bedsores start out as reddened areas that do not blanch when

pressed but will progress to ugly open wounds if blood continues to be cut off to the underlying muscle due to pressure. This is no time to worry about privacy or embarrassment - it is vitally important to monitor the condition of the skin over the entire body and to notify the Director of Nursing at the first sign of trouble and insist on a plan of correction for healing and prevention. Look under all bandages to see that care is given and that healing takes place.

***Mental Confusion**

Mental confusion is not to be expected with normal aging. If mental changes occur look carefully for the cause. Look first at your loved one's medications, for dehydration, or signs of infection. Don't let anyone label these symptoms as dementia or Alzheimer's Disease until everything else is ruled out and you have gotten a second opinion.

***Incontinence**

Federal regulations require that nursing home residents should be as self-functioning as possible and this may require bowel and bladder retraining programs. Because taking someone to the toilet is time consuming, short-staffed facilities may prefer to use incontinence products (adult diapers) even for residents who can control their elimination but are physically unable to get to the bathroom without assistance. Unnecessary diapering is emotionally devastating as well as expensive. On the other hand, when needed, the use of incontinence products may serve to keep a person ambulatory and *more* independent but they also require attention and changing as needed to provide good

hygiene and prevent skin breakdown. The law requires diapers to be checked and changed as often as necessary. (When diapers are prescribed for a Medicaid resident by a physician, the nursing home is required to pay for them.)

An indwelling catheter may seem to be the answer to incontinence but is, instead, a conduit for infection and should be avoided if at all possible. If incontinence is a problem it needs to be addressed in the plan of care and you may need to insure that the plan is carried out.

*** Restraints**

Today it is commonly recognized that physically restraining persons in an effort to prevent falling or wandering away results in both physical and emotional harm and actually requires closer staff supervision than freedom of movement. Being restrained in one spot for long periods of time can result in incontinence, bedsores, and permanent loss of independence and mobility.

Residents who try to free themselves from restraints often suffer more serious falls and injuries than they would have without restraints. This is especially true in the use of bed rails. Physically restraining a resident in a bed with a bed rail increases the danger of falls if frail or confused residents try to climb over them. In addition, there have been several deaths of nursing home residents who suffocated after becoming wedged between the edge of the mattress and the bed rail.

Do not, however, allow nursing home staff to put your loved