

Participating in
the Care of
Your Loved One



Family Handbook Guide For Long Term Care



Provided by the **Texas Long Term
Care Best Practices Committee.**

A guide to improving communication
between families and facility staff.



Compliments of the Texas Long
Term Care Best Practices
Committee

Best Practices Committee Members

Alzheimer's Association Coalition of Texas

Texas Association of Homes and Services for
the Aging

Texas Department of Human Services - Long Term
Care Regulatory

Texas Department on Aging, Ombudsman Program

Texas Health Care Association

Texas Nurses Association

▶ This handbook can be copied, but the content not altered except for personalizing the blank area on the back cover.

To Order An Original Call Either:

Texas Association of Homes and Services for the
Aging at 512-467-2242

Texas Health Care Association at 512-458-1257

Texas Department on Aging, Ombudsmen
Program at 512-424-6861

Helpful Web Sites and Phone Numbers

1. Adopt-A-Nursing Home
www.dhs.state.tx.us/communitypartnerships/adoptanursinghome/index.html
 phone number: 1-800-889-8595
2. Applications for Medicaid programs
www.dhs.state.tx.us/Forms/Form1200.html
3. Alzheimer's Association
www.Alz.org
 phone number: 1-800-272-3900
4. Texas Department on Aging, Ombudsmen Program
www.tdoa.state.tx.us
 phone number: 1-800-252-2412 (will connect to your local agency.)
5. Texas Department of Human Services
www.dhs.state.tx.us.
 Click on nursing home consumer information
6. Texas Health Care Association
www.txhca.org
 Care Line 1-800-388-2091
7. Texas Association of Homes and Services for the Aging
www.tahsa.org
 phone number: 1-512-467-2242
8. Complaints about long term care facilities
 phone number: 1-800-458-9858

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Expectations

Every care facility is unique, but some characteristics are true of all long term care facilities when compared to acute care facilities. There may be a larger number of people in less square footage resulting in an increased noise level. The number of caregivers to care-recipients will be lower than in acute care facilities. Resources (e.g. equipment, payor sources, supportive services) and geographical location may influence whether the care the recipient receives ranges from basic to state of the art.

It is normal for the family and the care-recipient to experience some degree of anxiety as the transition from home to long term care occurs. Commonly family members and care-recipient feel others are assuming control of their lives. Many other conflicting emotions may be experienced as well; this is to be expected.

When someone moves into a long term care facility the hope is that with assistance the care-recipient's physical and emotional health will improve and that this improvement will lead to independence once more. If the condition that created the need for long term care is chronic, reoccurring, and/or debilitating this may prove to be unrealistic. The care-recipient may continue to decline and eventually experience a natural death.

All residents do not die in long term facilities; however it is okay for death to occur there. Dying is a natural part of living. Care can change from curative to comfort care at the end-of-life.

Communication

It is important to be visible and involved with the care of your loved one. From the time of admission, communicate with the care facility management team and the direct care providers.

Participate in the development of the initial care plan, provide personal information: likes and dislikes, food preferences, usual mealtimes, bathing habits, sleep pattern, hobbies, etc.

If you have a concern, learn how the facility handles issues and communicate your concern clearly. Be certain your concern is not a misunderstanding or a miscommunication. The more you know about the formal and informal systems at work in the facil-

translated into a quality indicator report that contains resident characteristic data and a consolidated report on residents in the facility.

Quality Indicators are pointers that may indicate problem areas that need further review and investigation; however, they are not direct measures of quality.

To assess the quality of care it is important to:

- Make careful onsite visits especially during mealtimes and on weekends.
- Ask direct questions of the staff.

Understanding the Survey Process

The state survey agency, the Texas Department of Human services licenses all long-term care facilities — nursing homes, assisted living, ICF-MR/RCs, and state schools. The surveys determine facility compliance with state and federal Medicare and/or Medicaid regulations that safeguard resident health and safety.

Care facilities are inspected (unannounced survey) on average annually. In addition, the surveyor may visit periodically to investigate complaints. During an inspection, surveyors may talk with residents, family members or friends to discuss their views about the care the facility provides. You are encourage to share your positive opinions as well as your concerns.



Inform licensed staff of changes in your loved ones or roommates' mental status or behavior . This could be a sign of infection.

Restraints

Restraints can adversely affect one's dignity and independence. The use of restraints is highly regulated by state and federal standards. Restraints cannot be used solely at the request of the family. They cannot be used solely for safety or staff convenience.

To be used the below five items need to occur:

1. A specific medical need that is documented.
2. A written physician order.
3. The reason for the restraint must be stated in the care plan, including a plan to reduce or eliminate restraint use.
4. The risks and benefits of the restraint must to be explained to the resident and family before use.
5. Documentation must demonstrate that the least restrictive alternative is being utilized.

Research indicates that more severe injuries occur when restraints are used than when not. Restraints increase the risk for pressure sores, muscle loss and emotional trauma.

Family and staff need to work together to avoid using restraints and to determine alternatives to their use.

Quality Indicators/Measures

You may become aware of Quality Indicators/Quality Measures from the newspaper, internet or other sources. The QIs/QMs measure the condition of the care-recipients in each facility. The QI/QM data comes from the Minimum Data Set (MDS).



The MDS assessment form is required for all care-recipients in nursing facilities that are certified to participate in Medicare and/or Medicaid. The MDS must be completed within specific timeframes.

Once an MDS has been completed, clinical information is

ity the greater the likelihood of successfully resolving a concern.

Be involved with the Family Council, which is an independent, self-determined group of families and friends. Facilities provide a private place to meet. A staff person is designated to help and to respond to concerns. Staff and visitors may attend at the Council's invitation. Find out the leader's name and meeting dates. In addition, encourage your loved one to participate in the Resident Council .

Make every effort to resolve concerns, when this is not possible; you may seek outside resources such as the Texas Department on Aging Ombudsman program to assist in resolving the concern. (See contact information on page 13.)



Well-being/Quality of Life

Adjusting to a long term care facility is not easy, but with proper support from family, friends and the facility staff, your loved one may continue to experience quality of life. If you did not receive a copy of the Resident Rights at the time of admission, ask for a copy.

Ways you may help improve quality of life:

1. Make sure the staff knows the care-recipient's needs and preferences and ways that you met those needs before he/she came to the facility.
2. Inform the care planning team about your loved one's history—provide details such as past interests, hobbies, life philosophies, religious beliefs, likes/dislikes.
3. Encourage your loved one to get involved with activities. Go on walks.

4. Bring things to the facility that you can do together. Paint nails, listen to music, etc.
5. Read books or bring audio books.

Home Like Environment

When visiting, take time to interact with other residents, especially roommates. Not all of the residents have families who visit. Bring items from home that helps turn an unfamiliar room into an area that reminds your loved one of home. The list below offers some suggestion that may make this new environment more comfortable and home like.

1. Bring a photograph of your loved one when he/she was younger. We often think of ourselves at that age.
2. Bring a family photograph album and display family pictures.
3. Bring a favorite chair, if the room allows, or some other furniture item that adds a familiar touch.

Life Values

The care-recipient's medical, emotional and spiritual needs should be discussed and communicated to the care team. Find out what pastoral or counseling services may be available.

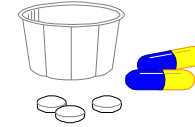
If you haven't discussed end of life preferences the discussion needs to occur. The facility staff can provide you with information concerning "advance directives".

When end-of-life care decisions have been made, inform your loved one's attending physician, the facility's social worker and the licensed staff.

When life expectancy is six months or less, Hospice care may be an option. Consult with the attending physician.



VI. Medications



Medications play an important role in the care and prevention of disease. Although medications provide benefit, they also may expose the care-recipient to problems. It is important to maintain ongoing communication with the facility nursing staff about medications.

Here are some ways you can help with medication management:

1. Use one pharmacy.
2. Try to keep orders for medication limited to one physician.
3. When you are informed of an order for a new medication, ask the purpose of the medication and possible side effects.
4. Some types of medications may require consent notification and approval before administration.

Infection Control

Vulnerability to infection is due partly to an age-related decline in the function of the immune system. Infections are common occurrences within long term care facilities, due in part to the number and age of the population. Some common infections are: urinary tract infections (UTI's), respiratory infections (influenza, pneumonia) and skin infections.

Even though some infections may be common occurrences, there are some ways to help reduce the risk of infection, such as:

1. Wash or sanitize your hands frequently when you visit.
2. Encourage your loved one, and roommate to wash their hands.
3. Encourage staff to wash hands.
4. Don't come to visit if you are sick.



come a routine part of daily care. Listed below are ways you may be able help.

1. Encourage and offer water or other beverages. Decreased fluid intake does not solve the problem of incontinence and can increase the risk of dehydration and infection.
2. Communicate to staff previous toileting habits.
3. Inquire about the need to go to the bathroom. If you can, safely assist to the bathroom and provide the necessary privacy. Note: Remind him/her not to wait until the last minute to call staff for help.
4. Allow time, don't rush the process.
5. Provide clothing that is comfortable and easy to arrange or remove to prevent accidents.
6. Make sure the pathway to the bathroom is well lighted and clear of obstacles.

V. Dementia

By age 85 almost half of the population will experience some symptoms of dementia, which has a slow onset. A person with dementia may have problems with mood or behavior, memory loss, difficulty performing familiar tasks (dressing, grooming, bathing, eating, cooking, driving, finances), misplacing things, judgment, decision making, problem solving and communicating.

There is no cure for dementia; it cannot be reversed. However, there are medications available that may slow the disease process. Ways you can help are listed below.

1. Do not argue or correct a person with dementia. Talk about the timeframe (year) he or she is discussing. Don't attempt to re-orient to the present time/date/year. Use validation rather than reorientation.
2. Treat care-recipients with respect and preserve his or her dignity (most important).
3. Talk to the social worker on ways to interact.
4. Contact your local mental health organizations, the social worker can provide a list.

Issues Associated with Aging

If you notice a change in your loved one's physical or mental condition notify facility staff. Some changes are age-related and unavoidable while other changes can be an early warning sign of an illness or progression of a chronic condition that requires medical treatment.

Report any of the following changes to the direct care staff.

1. Change in appetite.
2. Change in sleep pattern.
3. Change in behavior, mood.
4. Increased confusion.
5. Change in urine or bowel elimination.
6. Difficulty thinking or concentrating.
7. Loss of interest or pleasure in usual activities.
8. Recurrent thoughts of death or verbal statements wishing for death.
9. Change in ability to walk or transfer.

Other care issues or concerns are discussed on the following pages of the handbook.

I. Nutrition and Hydration

Decreased intake of food and fluid can contribute to a decline in physical health and increase the risk of illnesses. The elderly are more vulnerable to infection because of the age-related changes that result in the immune system being less responsive. Decreased fluid intake that results in dehydration can be life threatening.

Listed below are ways you may help your loved one receive adequate food and fluids.

1. Offer drinks of water or other fluid. Hint: Many prefer water flavored with a little juice.
2. Check with licensed staff before offering food or fluids to other care-recipients. They may be on a special diet.



3. Provide healthy snacks. Be sure to ask the facility about state rules on proper storage of snacks.
4. Inform facility staff of food preferences.
5. Plan visits to include mealtime. Encourage and assist in eating. Socialization typically increases the appetite.
6. Assist with oral hygiene or cleaning of dentures.
7. Mark dentures to prevent loss.

Also, be aware that as a person moves into the dying process it is natural to withdraw from wanting food or fluids. This should be care planned.

II. Mobility

If your loved one experienced one or more falls while at home and this is one of the reasons for admission to the facility, he or she may continue to fall in the facility.

If the care-recipient does fall, the focus for staff and family is to decrease the potential for injury, while increasing the emphasis on strengthening and safe mobility. Falling can be a common occurrence and does not necessarily indicate poor care. (See "Restraints" on page 9.) Some ways you can help prevent falls are listed below:

1. Physical exercise helps maintain strength and decreases the potential for a fall. If the care-recipient is ambulatory, spend time during visits walking together. If they are unable to walk, do simple exercises together. Ask a nurse or facility therapist about range of motion exercises.
2. Notify staff of wet spots on the floor or possible trip hazards.
3. Pick up items that fall on the floor.
4. Help keep room free of clutter.
5. Help keep room well lighted.

6. Remind and encourage the safe use of adaptive equipment such as walkers, canes, low beds, wheelchairs (lock wheelchair brakes).
7. Make sure your loved one's footwear is appropriate to the type of floor surface.
8. If the bed height is too high or too low, inform staff.
9. If you notice a decline in capabilities, inform staff.

III. Wandering in Unsafe or Unprotected Areas

Wandering in itself is not necessarily bad. In the past, perhaps your loved one enjoyed being outside, going for walks, etc. Please let the facility staff know this information.

However, wandering into unsafe areas or exiting a facility can create a risk. Listed below are some ways you can help decrease that risk:

1. When entering or exiting the facility, be observant of care-recipients around you and make sure the door completely closes.
2. If you have a concern regarding a care-recipient exiting the facility, immediately inform staff.
3. If you enter an area of the facility requiring a code to be entered on a keypad, be sure that care-recipients are not watching (they can memorize the codes). Don't speak the code aloud.
4. Ask the facility about safety devices, such as a wander monitoring system or other available devices.
5. If your loved one tends to wander outside, register them in "Safe Return", a national registry for persons with dementia. An ID bracelet is provided.

IV. Incontinence

Incontinence is not a normal age related change. The aging process can create other physical ailments that increase the probability of incontinent episodes. Consult the attending physician regarding medical causes of incontinence and treatments.

In long term care facilities, incontinence prevention must be-