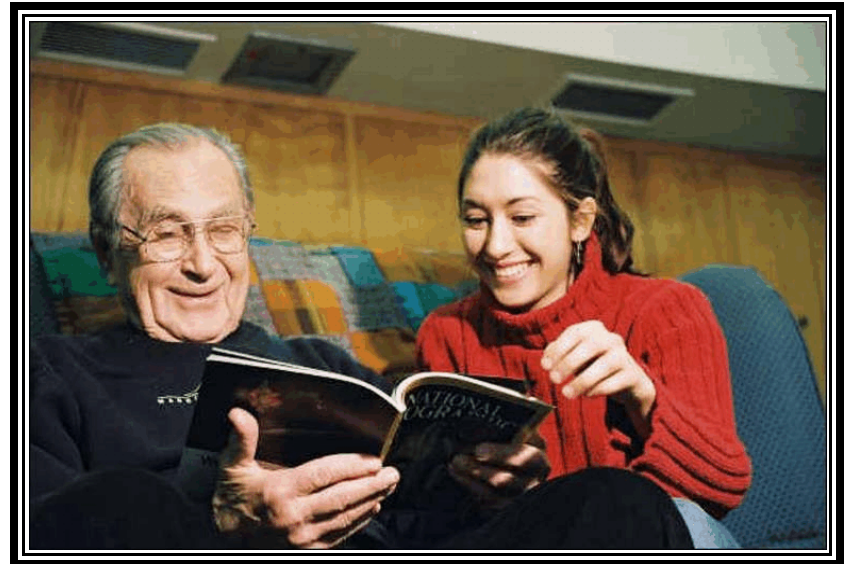


Family Guide To Long-Term Care



Optimizing Relationships

*Information for easing the transition to long-term care
and making your visits more enjoyable*

Promoting Excellent Alternatives in Kansas Nursing Homes
For more information go to www.ksu.edu/peak

Galichia Center on Aging

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785-532-5945 www.ksu.edu/gerontology

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Notes...

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A Short Introduction...

This booklet is designed to help you adapt to the changes that you will experience once you have helped your parent or loved one make the decision to move to a nursing home or other long-term care facility. Most of us are not ever fully prepared for the reversal of roles when our parents need our assistance to maintain their quality of life. For many of us the guilt that we carry when we become unable to provide this help hampers our own quality of life. We hope the information that is shared in this booklet will assist you in understanding that the feelings you are experiencing are shared by many and that there are things you can do to feel better. One is to ask for help. Staff at the nursing home that you and your loved one have selected understand your needs.

Lets Talk About YOU!

One of the hardest decisions that you will ever have to face is the decision to move a loved one to a nursing home. It creates a lot of stress for everyone involved. At least part of the reason for this is the negative



stigma that has been attached to nursing homes. Only a very small fraction of homes are deserving of this negativity and we like to think that all homes and the staff who work in them have the residents' best interests at heart.

Nevertheless, you probably had hoped that your loved one could stay at home until they died and now you're experiencing negative feelings. A number of years back a researcher studying people who were dying, recognized five stages that people typically go through in the grieving process. You may not have thought of it this way, but moving someone to a nursing home is experienced as a loss and you will need to grieve that loss. Read through the following stages of loss and the stories about people experiencing them and it might help you to understand your feelings:

Notes...

Notes...

5 Important Stages...

DENIAL: Denial is like a state of shock and individuals recover from it gradually. You may not really want to believe that your loved one has changed or that their health is failing. You may try to tell yourself that this is only a temporary state and that everything will return to normal soon.

A man recently placed his wife in the nursing home. Although he wanted to keep her at home, he realized he could not. Once she was admitted he did not come back to visit her for days at a time. The rest of the family could not understand his behavior as he had always been so close to his wife. The daughter decided to ask her dad why he was not visiting at the home and he replied, "I know she is there but if I do not go see her I can pretend she is somewhere else."

ANGER: You might feel angry with yourself because you think you've let your loved one down or may have broken a promise by bringing them to the home. This stage is the one that nursing home staff see frequently in family members. Often this anger gets misplaced and family members become angry with the help at the home.



Mary promised her husband she would never put him in the nursing home. He had always wanted to die on the farm. After a stroke left him partially paralyzed she had to admit that she could not care for him at home. After Ed moved to the nursing home, Mary visited at least once each day. During each visit she would always find something wrong with the care he was receiving. Even when everything was being done to ensure Ed's needs were all being fulfilled, she still found something to complain about. She did not seem to understand she was upset with herself for breaking a promise to Ed. Instead of finding a way to deal with the broken promise she pushed her feelings off onto the staff.

5 Important Stages

BARGAINING: This is a stage where you will be tempted to make deals. They might be with God (Please, God, I'll go to church every Sunday if you make my father well so I can take him home), with the resident, with another family member or with staff.



When asked how a family member knew that her mother was receiving good care at the home she said, "Each time I go to visit mother, I take some candy or cookies for her room. I like to let the staff know that it is there and that I want them to have it. I think they take better care of her when they know they are getting something in return."

DEPRESSION: If you experience some emotional or physical changes like changes in sleep patterns, changes in eating habits, decreased energy, loss of interest in normal activities, feelings of hopelessness, a persistent sad mood, irritability, or excessive crying, you may be depressed. Talk to your doctor about your symptoms and get help.

Staff members noticed that Mary Jean had changed since she'd first come to visit her mother at the home. She had lost weight, she seemed to have no energy and her bubbly personality had gone. Two of the aides were worried about her and they visited with the social worker to see if she would talk to Mary Jean about seeing a doctor.

To Sum It All Up...

Your role in the relationship with your loved one changes dramatically when they move from their old home to a new home in the long-term care facility. It may be hard to adjust at first to the changes but you can actively seek ways to become comfortable in the new setting. You can proactively discover the way to forge a new type of relationship with the assistance of care givers for your loved one's needs. You can add new and meaningful relationships with staff members, other residents, and other family members. You can actively participate in daily life at the home and you can learn ways to help this stage of your loved one's life to be as satisfying as any other.



Time For A Thank You!

You may have heard that in the course of our daily conversations with our own children we typically praise them less than ten times and criticize, find fault, and order them around hundreds of times. At the same time we are all aware of the differences positive and negative feedback have on emotional health.

The people that work at the home have difficult lives just like you. They don't make a lot of money from their jobs and many of them work not for the financial incentive but for emotional incentives because they have a need to care for others. A good nursing home organization recognizes that the residents will only be respected and honored if the staff are respected and honored. You have a very big role to play in this area. Learn to know and care for the staff.

It is not appropriate for you or the resident to give staff members gifts. Thank you notes or calls, praise and smiles, however, are much appreciated, especially if you pass the word on to the administration about the good deeds of staff.



5 Important Stages (cont)...

"Before my father came here he lived with me. It was so humiliating for him when I had to change his wet clothes. Now when I visit, I can talk to him like I used to. I can ask his advice and he can look me in the eye again."

ACCEPTANCE: When you reach a point where you realize that the placement was for the best then you will have reached acceptance. It is important to know that the sooner you can come to this conclusion the more likely it is that your loved one will also have the same realization.

Remember...

These stages of grief may occur in any order, several at the same time, for varying periods of time and may repeat themselves. Some people may skip stages and not everyone reaches acceptance, BUT understanding your feelings is the first step in this process.



Helpful Hints...

Help your loved one re-live special memories from their past. Here's a few suggestions to get you started:

- *Encourage talking about the old days - listening is very important.*
- *Tape their stories for younger generations. Their grandchildren can help write interview questions and the tape becomes a family treasure.*
- *Look through photo albums together or watch family videos*
- *Play music from childhood, teenage and young adult years.*

People To Know:

It sometimes gets confusing trying to know everyone who works at the nursing home and what it is that they do. Many nursing homes are trying to have what is called “consistent” staffing. That means that only a few people will be primarily responsible for your loved one’s care. This gives them a chance to develop a relationship with each other and the staff will have the opportunity to learn your loved ones’ needs and desires very well. These are the people you will want to get to know.

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There are many people in the home. The following is a partial list and what these persons typically do.

Certified nurse aide: you might also hear these positions called CNAs, or care attendants or resident aides. These persons have taken training to be certified to provide assistance with activities of daily living and some medical care.

Certified medication aide: also called CMAs, these are certified nurse aides that have had additional training so that they can give medications. They have learned about the effects of medications on the body and how to administer them.

Restorative aide: these certified nurse aides have had additional training to help residents with rehabilitative functions. They typically help the resident with exercises that are meant to help them maintain or improve their functional abilities.

It is important that you establish a caring relationship with your loved one’s caretakers. Ask them about their own families, their hobbies and remember their birthdays.

When You Have A Complaint

Try to be solution-focused when making a complaint. How do YOU think the problem could be solved? Try to get the staff member to make a verbal commitment about how the solution will be implemented and when you can expect results. Ask the staff member to follow-up with you at the end of the allotted time. If you are not comfortable with the resolution of the problem, then proceed to the next appropriate authority. If it is a nursing issue you may want to have a conversation with a licensed or registered nurse or the director of nursing. If it is more of a social or personal issue, you may want to speak with someone in social services. Seldom is it most efficient to go “right to the top” with your complaints.

Steps For A Successful Complaint

1. Go to the person closest to the resident or closest to the problem
2. Control your conversation and your body language so that the other person does not feel defensive but can concentrate on helping you to find a solution
3. Practice “active listening.” Repeat back what you have heard so you won’t make communication mistakes.
4. Be solution focused. Offers ideas for how you think the matter could be resolved.
5. Set a deadline when you would like to have feedback on the implementation of solutions
6. Seek a higher authority only when you cannot resolve the issue with the persons closest to the problem.
7. Heap praise on the staff member that helped you solve the problem.

When You Have A Complaint...

Despite best intentions, mistakes will be made. Sometimes, because of the need to be efficient in order to complete all the work that needs to be done, staff members may become task- instead of person-focused and the care they give your loved one is not what you would hope for. In these instances, and especially in the rare circumstances when real abuse occurs, you need to know what action to take.

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Some Tips For Making A Complaint

- ✓ Each nursing home will have policies regarding complaints but it is always best to go to the persons who are closest to your loved one, the nurse aides.
- ✓ When entering into a discussion it is important to think about how you conduct yourself.
- ✓ Be aware of your body language and the tone of your voice.
- ✓ Trying not to put the person you are talking to into a defensive position, carefully explain your concern.
- ✓ Allow them to express themselves while you listen carefully.
- ✓ To make sure that you fully understood them, repeat back to them what they have said, "Now I think I hear you saying that Mother's bed wasn't changed today because.... Is that correct?"
- ✓ Remember, many problems are made worse by poor communication.

People To Know (cont):

Licensed practical nurse: sometimes referred to as an LPN, these nurses are qualified to give medical treatments.

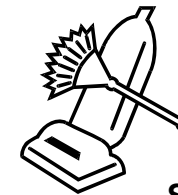
Registered nurse: also called Rns, these nurses have advanced clinical training.

Charge nurse: a charge nurse can be an RN or an LPN and is the head nurse responsible for a resident unit and usually supervises the clinical staff of that unit.

Director of nursing: she/he is responsible for directing the clinical services for the nursing home.

Dietary aide: this person is generally hired through the food service or dietary department and has roles in preparation and serving of food.

Feeding assistant: some nursing homes employ special feeding assistants whose only role is to assist residents with meals.



Housekeeper: housekeepers keep the building clean but can also be a great source of social interaction for the residents. Some nursing homes are now combining housekeeping and dietary duties.

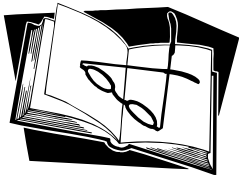
Social worker: the social services department is primarily responsible for insuring that the resident adjusts well to his/her new setting.

Family liaison: helps families to maintain optimal relationships with their loved one.

MDS coordinator: the person (generally a nurse) responsible for collecting and maintaining the Minimum Data Set records on each resident.



It's Greek to Me!



You may be hearing some terms or language around the nursing home that you don't understand. Here is a short dictionary for your use:

ADLs: Activities of Daily Living. These include: eating, dressing, transferring, walking, bathing and toileting.

Older people in nursing homes frequently need help with one or more of these

Agency Staff: When the nursing home needs more staff, they may hire temporary agency help.

CMS: Centers for Medicare and Medicaid Services, besides providing funding for residents that cannot afford nursing home care, this federal agency is responsible for many of the regulations that keep residents safe.

Culture Change: An attempt to change the way care is delivered so the residents have more choice and feel like they are living at home.

The Eden Alternative, person-centered care, resident-centered care and family-centered care are all forms of this new type of care.

DON: director of nursing.

KDOA: The Kansas Department on Aging.

This organization is responsible for the state regulations that keep residents safe in nursing homes and also for distributing Medicaid funding.

N__SING HOME, What's Missing? UR!

Families seldom "abandon" their loved ones to nursing homes. Most continue with loving relationships which sometimes are made stronger by the fact that the stresses of caregiving are alleviated by the staff. No matter how wonderful the new home is, however, there are some things that nursing home staff can never replace.

Families are responsible for keeping the resident connected to their past and their communities and for helping the resident to maintain their own sense of identity. You need to frequently ask your loved one to reminisce with you because it helps them in developmental processes associated with aging to think about their pasts and to become resolved that no matter what may have happened, it was OK and it's alright to move on from it. Usually, all you have to do to make this happen is to just be a good listener.

One of the things that improves satisfaction for residents in nursing homes is trips away from the nursing home. While the home will organize some trips, it will well be worth your effort if you can arrange as many as possible on your own. The staff will be happy to help you.



Where Should We Go?

- Take your loved one to a familiar spot like a park or the beach
- A dinner out with the family would be a welcome treat!
- Visit an old friend that would love to "catch-up."
- An outing to see a grandchild's school activity would be a lot of fun!
- Focus on a loved hobby - visit a craft fair or baseball game.

N__SING HOME, What's Missing? UR!

In one visit to a nursing home, a PEAK-Ed staff member met “Marjorie” who shared her memories of her weekly Friday and Saturday night rituals—dining at the local fried chicken restaurant. These dinners where she laughed and told stories with her family and friends helped to shape the course of her life in the home.

You can also get involved in the nursing home by volunteering. More individual activities are always appreciated. Help with or leading group activities is often welcome as well. The home may have a list that they have developed of ways that you may share your time and talents. If not, ask what is needed.

If the home you are involved in has consistent staffing, meaning the same staff work with the same residents nearly all the time, you might want to volunteer to organize monthly social events for the staff, residents and family members for one wing or one area of the home. This is especially appropriate if the home has committed to culture change and has developed “neighborhoods.”

Family Councils

A family council is a group of residents’ family and friends who have shared goals. Typical council goals include: education, support, advocacy and communication. See if the nursing home for your loved one has an organized family council.

It's Greek to Me! (cont)...

LTC: long-term care.

MDS: Minimum Data Set, (minimum hardly suits) this is a survey of 350 questions that is completed at least four times a year on each resident.



This question set covers their physical, psychological and social needs and is used to create a plan of care.

Ombudsman: This is a volunteer who serves as a liaison between family members, the nursing home and state agencies.

Plan of Care (may also be called care plan): a tool that all staff can use to insure that the resident gets the most appropriate care for their individual needs.

PRN: Provided as needed.

Helpful Hints...

Visiting a nursing home can sometimes be overwhelming. To make visits a meaningful experience here are a few suggestions:

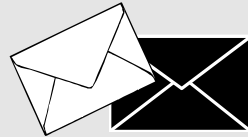
- *Knock on the resident’s door before entering and identify yourself.*
- *Keep communication eye-to-eye, if possible. Unless the resident is lying in bed, always strive for ways to speak with each other at eye level.*
- *Use adult language and tone when speaking to the resident.*
- *Respect the privacy of the resident’s roommate if they have one. Always ask before turning off a TV or radio.*
- *Be kind to every resident, not just the one you’re visiting. A simple wave and hello can really brighten someone’s day.*

Time For A Visit!

Many people are nervous about visiting a nursing home. The first few times sights, sounds and smells may feel unfamiliar and strange. That will get better with time but a little planning may help make your visits more comfortable for you, your loved one and the staff.

Visits don't have to last a long time. Just showing you cared enough to make the effort to stop by is usually the most important part of the visit. The following is a list of things that you might do with the resident when you stop by. This list was developed by the IDEA Institute:

- ✓ Walk around the grounds
- ✓ Read one story from the newspaper
- ✓ Open the mail
- ✓ Give the person a hand massage
- ✓ Help with a chore such as dusting off the family pictures
- ✓ Sing a song together
- ✓ Ask permission to bring a pet
- ✓ Share a snack
- ✓ Recap the news of the day



Time For A Visit (cont)!

If you aren't sure if an activity is appropriate, just ask for guidance from a staff member, especially if the resident has dementia. Staff members are trained to understand the best way of communicating and caring for persons with memory loss and will be happy to share with you ways to make your visits comfortable and enjoyable for you and the resident.

- ✓ Feed or watch the birds
- ✓ Water the plants or enjoy the gardens
- ✓ Flip through a photo album
- ✓ Straighten a dresser drawer
- ✓ Complete a quick word puzzle
- ✓ Put together a small jigsaw puzzle
- ✓ Create an ongoing craft project to work on a little bit at a time
- ✓ Write a letter to a family member—continue it on the next visit
- ✓ Sign birthday cards once a month

