

ABOUT THIS MODULE

Included here you will find a sampling of some of the pages out of this educational module which is intended for use by nursing homes who wish to promote more social, non-traditional models of long-term care. The intent of these modules is to assist organizations in implementing progressive, innovative approaches to care that should make a significant difference in the quality of care and the quality of life for those living and working in long-term care environments. Full copies of the modules in pdf format are available. Please contact us for the fee schedule for these modules at gerontology@ksu.edu.

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The development of PEAK materials was supported by the Kansas Department on Aging and the Kansas Department of Social and Rehabilitation Services through a Title XIX contract and matching funds provided by Kansas State University, Kansas Association of Homes and Services for the Aging, Kansas Health Care Association, and volunteers from the Long-Term Care profession.

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Revised December 1, 2003

Pioneering Change

**Family/Community
Education Module**



to

Promote **E**xcellent **A**lternatives in **K**ansas
Nursing Homes



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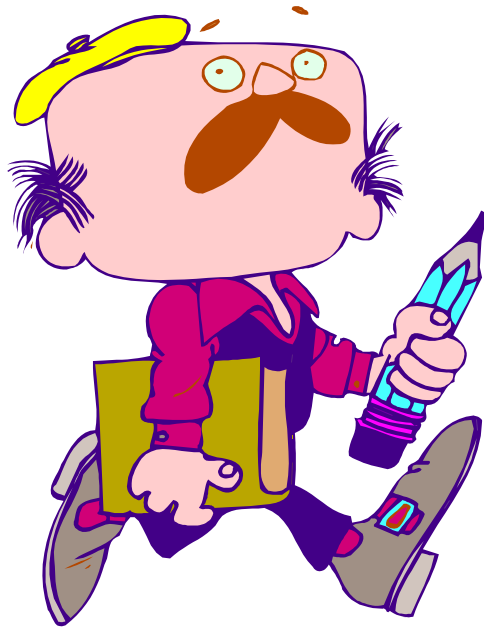


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Course Objectives:

1. To understand the emotions family members bring to long-term care.
2. To develop strategies for increasing family involvement.
3. To understand the facility's role in family involvement.





Family Involvement

Introduction

(Refer to the section on how to use the modules in the original “Culture Change Education Module”)

“Relationships are not only the heart of long-term care; they are the heart of life. And life should continue, wherever we live.”

-Carter Catlett

Williams

The quote above highlights the importance of relationships in long-term care. Often the focus has been on the relationships between residents and staff, and less has been done to help ensure the continuation of positive relationships between residents and their family and the creation of positive family-staff relationships. After the importance of family in the long-term care setting becomes apparent, it is evident that any existing barriers must be removed. Some of these barriers include lack of family participation in the facility and family-staff interactions.

Who Is Family?

People have many different definitions of the word family. These definitions might include things like who you consider family and the role of the family. It is important that staff can recognize the different forms a family can take.

Activity

Write your definition of a family here:

Now break into small groups and share your definitions. Look for similarities and differences. Write your combined definition here:

An alternative to writing definitions might be drawing pictures of what family looks like.

Family is defined in J. Ross Elshleman’s text, The Family, as a social group, a social system, and a social institution. The group is a collection of persons who recognize one another as family members.

When you look up the term family in a dictionary you will find multiple definitions. These may note that relations can be biological, emotional, or legal.



You probably saw many different definitions emerge. At the same time there were probably some shared ideas expressed by group members. The point of this activity is to show that everyone has a different definition of family and each of us is entitled to determine who we consider family.



Resources:

Eshleman, J.R. (2000). Marriage and the family: Disciplinary and theoretical approaches. In *The family* (9th ed.). Needham Heights, Massachusetts: Allyn and Bacon.

Family-centered Care. Definition of family-centered care. Retrieved February 12, 2004 from www.familycenteredcare.org.

What's My Job?

When family members at St. Joseph Village in Manhattan requested a "family job description," they wanted to more clearly define their specific roles within the community. Staff members at the Galichia Center on Aging helped them to draft the following. These statements comprise the beginning process of the family job description. Each of the neighborhoods (called courts at St. Joseph) are holding family meetings where families can provide input for the description. This may be a beneficial activity for staff, residents and family members in your organization.

Family Job Description:

- Work collaboratively with staff and residents to insure quality of life for all
- Maintain resident's identity by linking them to the community with visits, trips out of the home and reminiscing
- Help resident to maintain autonomy and control by helping them to make appropriate decisions about their care
- Report problems to court staff and work cooperatively with them to problem solve the issues. Seek attention from support staff outside the court only if the problems cannot be resolved in a reasonable amount of time.
- If designated, attend care plan meetings
- Support the staff by getting to know them and being personally concerned about them. Offer positive reinforcement for work well done
- Ask the staff if it is appropriate to assist other residents
- Volunteer
- Help with activities
- Help prepare food in the court kitchen
- Read to residents
- Become a member of the family council



The Burden of Placement

Placing a family member in long term care is among the greatest stresses a family may experience. Facility employees need to be sensitive to the feelings family members are dealing with during the transition period. These feelings often affect the interaction with staff. Family members interviewed about moving a loved one to a nursing home reported experiencing feelings of loss of control, disempowerment, guilt, sadness, grief, and failure (Kellest, 1999). Even though they are not losing the family member to death they are grieving. Kubler-Ross's stages of grief (as cited in Kastenbaum, 2001) denial, anger, bargaining, depression and acceptance, can be applied to the placement experience for some families.

Denial comes in many forms and is a primitive defense. It helps protect a person from danger or threat. Denial is like a state of shock, and individuals recover from it gradually. Denial shows itself in many forms of behavior. In your facility you may notice denial surrounding the placement or a family member denying him/herself the right to separate from the guilt.

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 see her for days at a time. The rest of the family commented that they were surprised that he was not coming to see her since he had always been so close to her. The daughter decided to ask her dad why he was not visiting. He replied, "I know she is there but if I do not go see her I can pretend she is somewhere else."

Anger is the next phase and is multi-dimensional. Family members display anger with themselves when they believe they let their loved one down or broke a promise to them.

"Are you going to put me in a nursing home?" "No, Mom/Dad, I'll never put you in a nursing home."

This question and response show a typical promise. They may also be angry with the facility for taking their family member away or for not accommodating the resident's needs. This anger can make families more difficult to deal with since they may be unaware of the anger they feel toward themselves and displace it onto front-line staff. By using anger they can regain control over the situation. Tolerating the anger in a professional manner is important, since it is a normal part of the grieving





process. Some anger may also be focused on other family members if they are perceived as not helping or at the resident if he/she is not adapting to the new environment. The following example gives some insight into how a family member's anger might be experienced by staff.

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 was admitted, 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 done to ensure all Ed's needs were being fulfilled, she still found something to complain about. She did not seem to understand she was upset with herself for breaking her promise to Ed. Instead of finding a way to deal with the broken promise she pushed her feelings off onto the staff.

Bargaining is the stage in which the family members attempt to make deals. These deals may be with God, the resident, another family member, or even staff. In the following example a family member was asked, shortly after admission, how she ensures her mother is getting good care.

"Each time I go to visit mother, I take some candy or cookies for her room. I



like to let the staff know 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 may be experienced due to



the toll stress, strain, fear and guilt can take on the family member's well being. For an older adult who lives miles from the facility, frequent trips to visit the resident may require more physical effort than his/her previous routine. Family members may also experience depression due to the loss of their familiar role and from physical or mental exertion. You might notice a drastic change in the visiting patterns of a family member if they are experiencing depression. The family member might also begin neglecting him/herself both physically and emotionally.

Acceptance represents the end of the person's inner struggle with the placement. At this point, the family members realize the placement is for the best. They forgive themselves for putting their loved one in the nursing home and accept their new role. This is not necessarily a happy state, but it is a realization that it had to happen and will be okay. The following example shows



that the daughter has realized placement was the correct decision and is able to focus her energy on the relationship with her father again. This is the type of outcome our efforts should steer all families toward.

“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.”

(Helphan & Portor, 1981 p. 57)

The stages of grief may occur in any order, or concurrently, for varying periods of time and may repeat themselves. Family members will not work through the stages in the same time frame and not all will reach acceptance. A family’s understanding, or lack of understanding, about what they are experiencing can mean the difference between reintegration or more rapid decline for the resident, and may lead to a long term grief reaction for families (Greenfield, 1984).

Resources:

Greenfield, W. (1984). Disruption and reintegration: Dealing with familial response to nursing home placement. *Journal of Gerontological Social Work*, 8(½), 15-21.

Kastenbaum, R. (2001). Death: Transition from life. In *Death, Society, and Human Experience*. Needham Heights, Massachusetts: Allyn and Bacon.

Kellett, U. (1999). Transition in care: Family carers’ experience of nursing home placement. *Journal of Advanced Nursing*, 29(6), 1474-1481.

Helphand, M., & Porter, C. (1981). The family group within the nursing home: Maintaining family ties of long-term care residents. *Journal of Gerontological Social Work*, 4(1), 51-62.



Helping Families Cope

“I just wish I would have known my feelings were normal; I felt so alone.”

Helping families cope with their feelings is an important initial task not just for the social worker but for all staff. The impact of not helping families cope with the transition is devastating for both the resident and their family.

You may be wondering what factors influence a family’s ability to cope with change. Greenfield (1984) notes the way individuals deal with change is based on two factors: a person’s coping ability and the way in which the change process is structured. As you can see, the nursing home community has no control over the former, but can affect the latter by ensuring a responsive environment. It plays a vital role in creating and maintaining support during the transition. The transition can be eased by ensuring families are provided with easily understood information and demonstrating that their contributions are valued. Family programs (to be discussed shortly) offer valuable opportunities to guide families through the transition and give them the opportunity to discover their feelings are normal.

After gaining an understanding of what families are experiencing and realizing how difficult the transition can be, there is

a tendency to sympathize with their situations. Sympathy refers to feeling sorry for the person and accepting where they are. It does not serve to motivate. Empathy deals with seeing the situation from the person’s perspective as well as being able to see the differences between what the person sees and what is going on in his or her environment. Empathy allows the staff caregiver to work actively with family members’ concerns and to assist them through the process.

During a visit to a nursing facility two staff members were overheard discussing the wife of a resident. One staff member states that she, “feels really sorry for her.” The other staff member acknowledged she was going through a tough time, but asked her co-worker what they could do to help her.

While the first worker was concerned about the family member she did not consider what could be done to help. Her statement was a mere reaction to the situation while the other staff member was pro-active. Part of having empathy is being pro-active to the other person’s situation.

Read Between the Lines

With a better understanding of the emotions families are bringing into the facilities it is time to take a look at the



nursing home community into which the new resident has moved. It is important to recognize that the policies and procedures your facility has in place will dictate the amount and type of opportunities families have for involvement with their loved ones. It is crucial that policies are “family friendly” and reflect the correct image. A simple example of this can be seen by looking at a facility’s family booklet:

“We allow residents to go on outings with family. Residents must be signed out and a time of return given prior to leaving the building.”

Think about that statement from the family’s perspective. Should you have to have permission to take your mother to lunch or the movies? Is it absolutely necessary to know when the resident will return? This policy language, while well intended, makes taking a family member on an outing seem like checking out a book. Perhaps simply by changing wording and humanizing the policy, family outings could be encouraged by taking away the fear of “late fees” or repercussions. We want families to take their loved one out of the nursing home for meals and other family activities. A “family friendly” policy might read something like this:

“Outings with family are encouraged and we will be glad to help facilitate them as



necessary. Please let staff know when you leave and return so we don’t worry.”

Since policies should be designed to encourage quality of life, not to impede it, satisfying guidelines while being family friendly is easily attainable.

Resources:

Greenfield, W. (1984). Disruption and reintegration: Dealing with familial response to nursing home placement. *Journal of Gerontological Social Work*, 8(½), 15-21.