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

Returning Control to Residents Education Module

to

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

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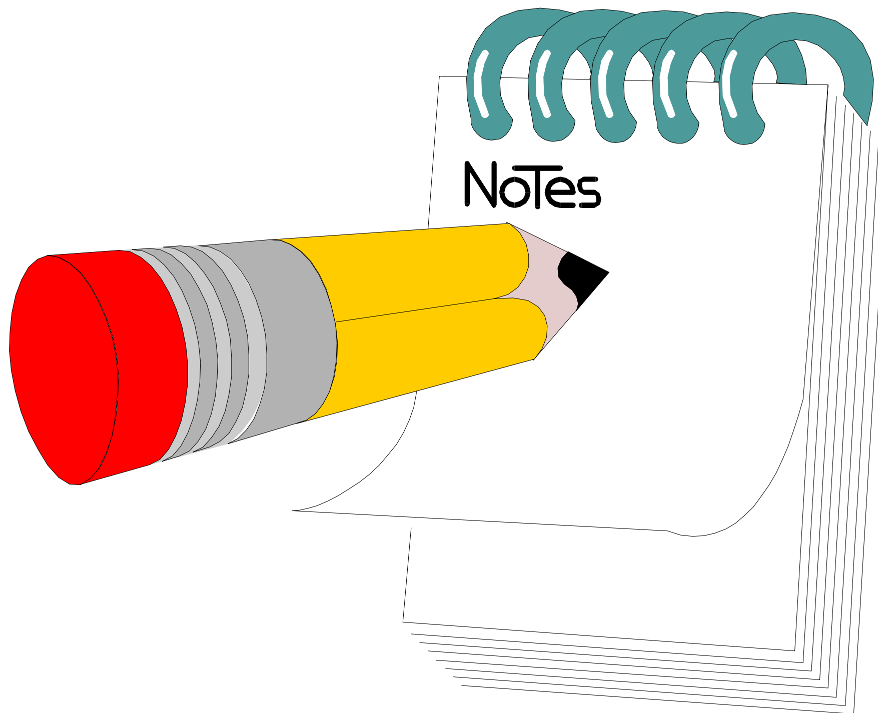
Course Objectives:

1. To understand general concepts of resident control and autonomy.

2. To develop strategies for enhancing resident control and autonomy

3. To understand the ability to work with regulations for resident autonomy and control.

4. To raise awareness of desired outcomes from resident-centered care.

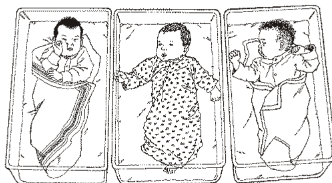


Returning Control to Residents

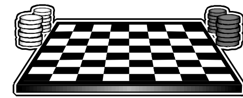
Introduction

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

Maybe I shouldn't have looked back, but the all-purpose room had a big window facing the parking lot and I couldn't help glancing in to see if my mother was watching me leave, waving as she usually did at all our good-byes. Thankfully, this time she wasn't watching so she did not see the tears on my cheeks or the shock I felt at not being able to instantly find her in the little gray-headed wheelchair-bound armada gathered around in a circle, all with lap robes and shawls. We had always laughed over her hospital "nursery room" story about how she couldn't pick her own babies out from the other newborns, but now the story had turned and was no longer amusing. In one shattering afternoon her individuality seemed to dissolve right before my eyes.... (excerpted from "A Nursing Home Odyssey" by Mary M. DeShaw, 2002, http://garnet.berkeley.edu/~aging/odyssey.html)



The honoring and sustaining of individuality can be in short supply within the nursing home environment. Caregivers generally are well-meaning persons who desire to express their compassion for the residents they serve. Unfortunately, for many of these caregivers the pressures of the job, the tasks that HAVE to be done, outweigh the opportunities to provide resident-centered care. For the best of them, the resident-centered focus sends them home at night feeling like they haven't achieved their goals for the day. One nursing home caregiver has compared her work role to her role as a mom. She never feels like she has enough time. The work is unfinished when time isn't found to read the paper to Charlie or to play checkers with June. The alternative, however, to resident-centered care is residents who are lost in "the wheelchair-bound armada gathered around in a circle."



This module is all about recognizing the individuality of residents and the staff who serve and support them. Many nursing homes have become "mindless" cultures where practices are repeated over and over again simply because they always have been, not because they are the most appropriate for the moment. Bathing is a case-in-point. Traditional bathing techniques (tub baths and showers) have frequently been a trigger for problem behavior. Alternative methods for keeping clean have been

demonstrated as safe, effective, and less problem inducing, and yet many caregivers cannot give up their assumptions about how bathing should occur within the nursing home environment. Many other examples can be found that demonstrate notions about how nursing home services must be delivered, such as waking persons in the morning based on the location of their rooms, and assumptions about therapeutic diets. The focus on these tasks has de-emphasized the persons who are the recipients of the tasks.

Defining the Terms

It is important to consider carefully the terminology adopted by your nursing home since it can reflect the way the organization views residents and may impact determinations of individual differences. Each of the following terms has a slightly different meaning and you will want to choose the one that best matches your philosophy of care.

- **Resident-directed:** This philosophy was developed at Mount St. Vincent in Seattle. Leaders in a traditional model nursing home wanted to change the way they provided care so they asked residents what they desired. Resident input, constantly sought by staff, drives the culture changes. **“Resident-controlled**” may be a derivative of this model.

- **Resident-centered:** This term implies providing care that is intended to be based on what the resident desires but may also be based on what staff members “think” they desire. It is important to consider the use of this term and philosophy carefully. Staff feelings should never replace suggestions and ideas from the persons living in the home. The input of residents should be actively sought.

- **Person-centered:** This philosophy was first implemented in the developmental disability movement. As it has been adopted by long-term care environments it may mean extending the focus on the needs and the desires of the residents to all persons in the nursing home community. In other words, staff are viewed as being as important as the residents. It implies that all members of the community work in collaboration to develop plans that are best for all involved.

- **Regenerative community:** This term was coined by Barry Barkin from Live Oaks in California, who believes that we should promote the notion that ALL people, no matter what their needs, can continue to grow until they die. This idea is demonstrated well by the following story. You may want to use it for an opening activity in a small group training session.

This is an often repeated story of a nursing home administrator who was well known for the kind, compassionate, and innovative care that he and his staff provided within his nursing home. He was frequently asked to speak at conferences and in-service trainings. At one of these meetings he told the following story:

Sarah was a difficult person to care for. Her behavior was erratic and she had difficulty making her wishes known. All of her physical needs had to be provided by others. If what she spoke was a language, it wasn't from this earth. Sometimes she was so delightful and engaging that people begged to take care of her, while other times it seemed impossible to make her happy. Sarah frequently kept people from sleeping at night with her crying and screaming. She had to be fed and many times the food ended up in her hair and all over her clothes. She was constantly drooling and wore a bib to catch the spit upon her chin. She could not change her own clothes and was incontinent.

The administrator asked the small group of staff members what they would do for a person like Sarah.

(You may wish to have members of your staff contribute to the discussion at this point, having them describe similar situations and what staff members did for this person)

In the story, one staff member replied, "Oh, we have seen many residents like Sarah. There isn't much you can do for them but attend to their physical needs and try to love them." The other staff members nodded in unison.

The administrator listened attentively and then said, "but.....Sarah is my eight-month-old daughter."

(Author unknown)

What does this story mean to you?

Assumptions about frailty: as this story was told, you created a picture of Sarah in your mind. Because you work in a nursing home, it was natural for you to think of a person that may have fit Sarah's description. A person who can do so little for herself or himself can easily appear to have no further value other than perhaps for our own compassion. In fact, many of us create assumptions about ability and worth from the moment a person becomes a resident. Simply moving to a nursing home suggests dependency and the lack of ability to be responsible for oneself.

Societal comparisons of the beginning and end of life: A second point is that we frequently describe Alzheimer's dementia as a reversal of the developmental process. The older person loses in reverse order to what he or she gained in infancy. (For more information about this see Barry Reisberg's work as

listed in the references. His work can be very good in helping families to understand these processes). However, there may be danger in this description. If we believe this to be true we may begin to believe that older persons at the end stages of life have the same needs as children at the beginning and can be treated like them. This could hardly be true.

Renee Rose Shield (2003), in an essay about dependency, writes about the tendency that Western civilizations have to judge very old and dependent adults as being similar to children. However, dependency in children is applauded while it is scorned in older people, and sets up an imbalance between the caregiver and the dependent person. “The payment for the dependency is acquiescence and gratitude” (p.127). Lack of control, she further states, may be the basis for the shame that accompanies dependency.

Assumptions about the inability to grow at the end of life: It is easy to care for the dependent child because one assumes that the child will grow into independence. Indeed, caregivers do everything they can to foster autonomy within children so that they can develop into unique individuals. If we make assumptions about the inability to grow at the end of life it supports our inclination to focus on the tasks rather than the persons involved.

Rosalie Kane writes, in Everyday Ethics: Resolving Dilemmas in Nursing Home Life:

...In childhood, people are typically expected to become unique individuals even as they learn to assume defined social roles. In old age in the nursing home, however, people are expected.... to homogenize their individual traits and eccentricities to a remarkable extent in order to fit into a bureaucratically defined behavioral norm... This cultural expectation makes it possible... to exhort residents toward conformity with the institution and to rationalize many kinds of intrusions as necessary for the residents’ own good (p. 23).

What is our role with frail elders?

Recently several administrators worked together to try to develop a theory of long-term care. They were stalled, perhaps because we as a society lack a theory of what role frail elders are meant to play in society. Lacking this theory, perhaps long-term care theory needs to be couched in terms of what we as caregivers need to be able to feel in working with frail elders. This appears to be the impetus for true culture change. The leaders of change have been enlightened to the “need” to provide care for elders in a way that was more aligned to their beliefs about humanity. They didn’t feel satisfaction working in the current culture.

Let's return to Sarah.....

Let's return to the example of Sarah and ask the question "if the staff who answered how they would care for Sarah were a culture changed home, how would they have answered differently?"

A culture change organization may have answered in a manner that was observed in a Kansas nursing home. A visitor was touring the facility one day with an administrator when he asked why a particular resident was out of bed. She appeared to have no communication skills and had been a resident of the home for years and he'd never seen her up before. The staff member pushing the resident in a wheelchair explained that there had been no clear reason stated for why she needed to be in bed. The staff as a group decided to try dressing her and getting her up to see how she reacted. They felt that she was more responsive and seemed to enjoy the activity.

Oftentimes, knowing how to take care of residents as they would desire is a trial-and-error process. It may also help to ask family members to assist staff members to understand the things that their parents appreciated in their life before the nursing home. If these strategies have been tried and were unproductive, staff members may wish to implement "substituted judgement." What would they want done for them in a similar situation?

Another statement about language:

Terms for the type of care offered are not the only words that need to be examined when adopting new philosophies. A good way to start changing is to examine the written materials produced by your organization. Do mission statements and newsletters accurately describe the work that you do? Do job descriptions and job titles reflect new models of care? For example, the terminology "charge nurse" may not fit within a design where staff members share responsibilities for care decisions.

Many nursing homes are adopting smaller units of residents and staff. These units have been called neighborhoods, households, courts, clusters, and communities. Each of these terms implies a different type of philosophy. For example, households may imply for some hearing the term a more intimate environment and more isolation than would the terms neighborhood or community.

Returning Control Activities

Group Activity: (This activity may work well as a group activity where participants brainstorm and share options from group members and then select the words that "best" suit the organization)

Following is a list of terms commonly used in traditional model nursing homes. For each provide an alternative option:

facility:____________________________pat
ient:____________________________
charge nurse:_______________________
nurse aide:_________________________
diaper:____________________________
feeders:___________________________
wing or unit:________________________
admit or place:______________________
discharge:__________________________
lobby or common area:_______________
nurse's station:______________________
housekeeping:_______________________
agitated:___________________________foo
d service:_______________________
ambulation:________________________elop
ement:_________________________

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