

## Person Centered Care and the Family Caregiver

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www.thegreenhouseproject.org



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**Person-Centered Care is about a Change in the Culture of Long Term Care**

### Culture

A set of values, beliefs, customs and traditions, language, and way of doing things within a group

### Change

The act of making different

To alter

To transform



## At the Center of Good Care



What is this thing called person-centered care?

Valuing people and those who care for them  
(V)

Adapted from the model by Dawn Brooker, Ph.D



## What Do Elders Want?

Kindness, Caring, Compatibility and Responsiveness

To know the caregivers

To like them and to feel safe,

To feel liked and respected by them



**RELATIONSHIPS!**



Treating people as individuals  
(I)

Adapted from the model by Dawn Brooker Ph.D



**Who am I?**

What is most important to you in your life?

What are you the most proud of?

Tomorrow you are going to enter a nursing home. The person next to you will be your caregiver. What do you want this person to know about you? What is important to you? What is not negotiable?

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Looking at the world from the perspective of the person (P)

What would you think if...

Adapted from the model by Dawn Brooker

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Providing a positive social environment in which the person can experience well-being (S)


Adapted from the model by Dawn Brooker, Ph.D

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**Philosophy of Person-Centered Care**

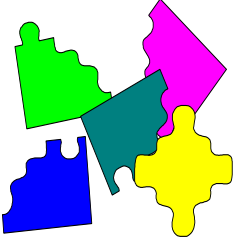
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- Facilitate knowing
- Foster reciprocal relationships
- Place decisions with elders or as close to them as possible
- Provide privacy
- Build intentional community
- Support a life worth living: engagement, enjoyment
- Create a sense of home



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- Some family members have stated they would rather die than have their family member enter a nursing home!
- Older Adults in the United States say they would rather die than enter a nursing home.



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**Language that Shapes Relationships and Expectations**

Language And Culture	Admit/ Admission
	Placement / Place
	Institution
	Transfer
	Facilities
	Beds
	Feeders
	Behaviors
	Dementia Unit

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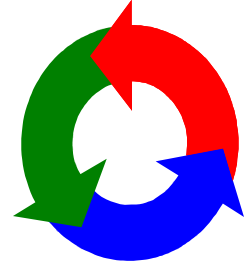
## The Family as a System

- The family is a social system governed by rules and principles.
- Families are composed of individuals held together by kinship, legal, and historic ties.
- A family is a dynamic social system in that relationships among members change.
- A change affecting any one member affects all other members and the family unit as a whole.

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## Family Life Cycle

- The family as a unit and not just a collection of individuals can be extended to the notion of a life cycle of the family.
- The key to understanding the family is understanding relationships.
- No other system operates like the family



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## Family in Later Life



- Family relations continue to be important throughout later life.
- Family members are the primary caregivers for older adults.
- Death is expected but disability and dependency is not.

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## Family Issues Related to Nursing Home Decisions

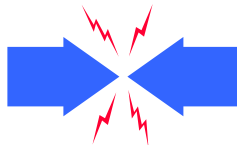


- The decision to enter a care setting
- Entry into the home
- A move to a more intensive level of care
- Death

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## Decision to Move to a Nursing Home

- The decision is difficult for any family.
- More difficult if the person entering is not active in the decision.
- Moving to a nursing home results in huge feelings of loss of control for many individuals.



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## Helping Through Each Transition

- Are there procedures in place to meet the needs?
- Has staff been educated on the stress involved with each transition?

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## Decision to Move-In

- Understanding emotions involved in decision
  - Guilt
  - Fear
  - Mistrust of staff
  - Anger

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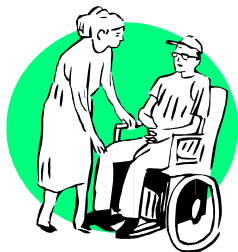
## Decision to Move to Care Setting

### Recognize emotions involved in being a caregiver

- Anger at the person and situation
- Loss of person
- Sense of failure
- Change in roles
- Denial of severity of the problem
- Anxiety
- Sense of purpose

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## Starting the Relationship – Supporting a Culture that is Person-Centered



- Staff is warm and accepting
- Show real concern for the new resident
- Questions and concerns addressed and followed up on in a timely manner
- Consistent and recognizable staff
- A cultural and ethnic compatibility

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## Move to Care Setting

### Prior to the Move-In

- Education on the disease process
  - What to expect through the course of the disease
  - Symptoms the person is experiencing
  - Communication techniques
  - Common behaviors

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## Move to Care Setting

### Prior to the Move-In

- Education on the needs of the person
  - Develop sense of person and what approaches and services best meet needs.
  - Know life story, likes and preferences, before Move-In day
  - Begin partnership with family members as welcome new team members

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## Move to Care Setting

### Prior to the Move-In

- Education on a specific program
  - What to expect
  - Who to turn to for support
  - How to visit

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## Move to Care Setting

### Prior to the Move-In

- Education on Move-In day
  - Prepare family for what to expect
  - How to prepare the person
  - What to bring
  - Who should come
  - When to visit again

## Moving In...



The first hour,  
the first day,  
the first night  
the first week!

## Move to Care Setting

### Move-In Day

- Readiness on all levels
  - Staff
  - Family
  - Environment
  - Time of day
  - Follow up calls to family members on adjustment

## Move to Care Setting

### After the Move-In

Continue education

- On the disease process
- On emotions which are commonly felt
- On the program
- Provide reading material
- Have videos available

## Move to Care Setting

### After the Move-In

- Provide ways for family members to connect with each other
  - Family Support Groups
  - Family parties
  - Family mentoring program
  - New family orientation

## Move-In, Making It Home

Provide ways for family members to connect with the staff

- Social gatherings
- Care plan meetings
- Encourage to participate in daily care activities
- Include in staff training meetings
- Establish a formal grievance process

## Moving In, Making it Home

Provide ways for the families to connect with their family member

- Social gatherings
- Invite to activities
- Provide objects and activities for visits
- Provide quiet space for visits
- Invite on outings
- Keep family informed on loved one's well-being

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## What's a Staff Member to Do?

- **Introduce yourself**
- **Greet the resident first**
- **Be open to the questions and concerns of the resident and family**
- **Help them get comfortable and oriented to home**
- **Address any concerns or needs immediately**

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## Family joins the facility's team when...

- **The organization supports the family to join in daily life,**
- **Can access and use systems and services,**
- **Feels comfortable in home and staff,**
- **The resident begins to live a normal life in the home and seems to thrive.**



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## Change in Condition of Elder

- Provide education on common changes
- Help family recognize changes

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## Change in Condition of Elder

Old Culture of Care  
Moving resident to another level of care  
Pro's and Con's

If Move is Unavoidable...

Recognize move as a loss for elder and family

Provide support before, during and after move

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## Change in Condition of Elder

If Move is Unavoidable

Develop a system for moving person to a new care setting

- Special Care Plan Meeting
- Maintain relationships with current staff
- Introduction to new staff
- Have new staff learn what made this person special

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## Death and Dying

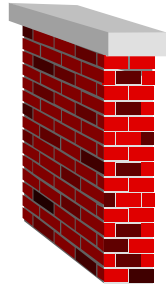
- Provide support and education during the dying phase
- Help family to make end of life decisions
  - Feeding tubes
  - DNR
  - Infections
  - Hospitalizations

## Death and Dying

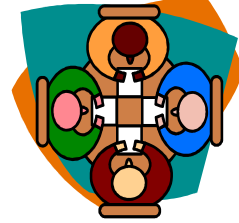
- Support families continued involvement with loved ones
- Respect privacy with resident
- Encourage families to share emotions
- Recognize families needs for support and control

## Communication

*Strategies to Break  
Down Barriers and  
Build Relationships  
Between  
Staff and Families*



## Communicating With Families



### *Effective Listening Skills*

- Encourage dialogue through eye contact and expression.
- Focus discussion on the information needed.

### *Understanding Emotional Behavior*

- Calmly acknowledge the emotional behavior
- Describe the effects that the emotional behavior has on you and on the discussion
- Determine whether it is possible to continue the discussion in a constructive way
- Propose an approach for jointly refocusing on the issue
- Express support and reassurance