THE UNIVERSITY OF IOWA

IOWA GERIATRIC EDUCATION CENTER

INFO-CONNECT

Family Involvement in Care

For Persons with Dementia in Long-Term Care Facilities

The Facts . . .

⇒ 50 to 70 percent of persons living in nursing homes have dementia.

⇒ Although family members seek assistance for care of their relatives, they maintain an interest in quality of caregiving.

⇒ Long-term care staff as well as families report many difficulties sharing the caregiving role.

Family Involvement in Care Intervention

The Family Involvement in Care (FIC) intervention refers to a strategy that partners family caregiver(s) and long-term care facility staff to provide the best possible care for a person with dementia.

One key to the FIC intervention is for both parties to continually negotiate and clarify their expectations to establish mutually satisfactory roles and relationships.

Another key is for staff to help family members choose the type and frequency of activities in which they want to participate.

Benefits of FIC Intervention

Benefits can be seen from the FIC intervention for family and staff, as well as for persons with dementia.

For Family and Staff

- Improved staff attitudes about families
- Decreased family caregiver guilt and burden
- Improved communication between family and staff

For Persons with Dementia

- Improved quality of interaction with families
- Increased therapeutic and diversional activities
- Increased preservation of individual identity

Risk Factors in Care Relationships

Both the person with dementia and the family caregiver(s) are at risk for unsatisfactory relationships and care. Families may experience conflict with staff over competing priorities. Without family involvement in care, long-term care facility staff may unintentionally neglect aspects of caregiving that are important to both the family and the resident.

Situations that put the person with dementia or their families at risk include:

- Family caregiver's assumption of a new role once staff becomes the primary caregiver
- Change in the type of care services or resources available
- Change from care in a familiar environment to care in an unfamiliar institution
- Change in care providers
- Deteriorating mental or physical capacity of the person with dementia
- Deteriorating physical or mental capacity of the family caregiver(s)
- Traditional expectations of staff that families are visitors and, therefore, minimally involved in caregiving
- Institutional barriers (e.g. lack of staffing, policy, procedures, or environmental structures)
- Resident and family's negative feelings about the new care environment

Information to Share

For families and staff to form successful family involvement in care partnerships, the following information should be shared about the person with dementia, the family caregivers, and the formal care provider.

Person with Dementia

- Date of admission to new care situation
- Cognitive function status
- Usual behaviors and activities
- Basic and instrumental activities of daily living
- Medical and nursing diagnoses
- Plan of care

Family Caregivers

- Date of admission to new care situation
- Reason for change in care situation
- Filial relationship of family member to person with dementia
- Primary caregiver at home
- Employment status
- Degree of family support
- Other social support
- Other family roles/obligations
- Feelings about new care situation
- Frequency of caregiving
- Care provided
- Ability to provide care (physical/emotional)
- Problems encountered in providing care
- Expectations for continuing participation in caregiving
- Expected frequency of contact
- Major concerns about new care situation

Formal Care Provider

- Type of setting
- Plan of care for person with dementia
- Philosophy of care of persons with dementia
- Policies regarding visitation
- Policies regarding family participation in caregiving
- Presence of family support group
- Attitudes about family participation in caregiving
- Expectations of staff for family participation in caregiving
- Staff knowledge about dementia and care of persons with dementia

For Additional Information about the FIC Intervention

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Specht, J., Kelley, L., *et al*. (2000). "Who's the boss? Family/staff partnership in care of persons with dementia." *Nursing Administration Quarterly, 24*(3), 64-77.

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Implementing the *FIC* Intervention

The FIC intervention is accomplished by establishing and implementing a Partnership Agreement which consists of four key phases:

- Orientation of family and staff;
- Education of all care providers;
- Negotiation and formation of the Partnership Agreement; and
- Ongoing evaluation and renegotiation of the Partnership Agreement.

Orientation

The purpose of the orientation phase is to establish a foundation of the FIC intervention. There are three important steps in this phase:

- A formal care provider who will act as nurse care manager (NCM) is identified.
- The NCM visits with family to identify primary family caregiver(s).
- The family caregiver(s) is taken on a tour of the care environment, reviewing philosophies and policies and discussing expectations and concerns.

Education

The purpose of the education phase is to educate family and staff regarding general principles of caregiving as well as the more specific principles associated with caring for someone with dementia. The following are suggested components of this education:

- Communication and visitation strategies
- Role adjustments required for family members and staff
- Therapeutic approaches to facilitate quality of care in a new care situation
- Negotiation and partnership information
- Negotiation skills for formation, maintenance and termination of partnership
- Role playing to practice negotiation and partnership agreement

Negotiation and Formation

Family members and staff review, discuss, agree upon, and document the goals and approaches for care of the person with dementia.

The negotiated Partnership Agreement specifically documents the plan for both family member and staff care provider involvement, as well as the frequency and anticipated length of time for each of the activities.

Ongoing Evaluation and Renegotiation

The care setting influences the frequency of evaluation and renegotiation. For example, in the nursing home setting, this is achieved by discussions between the NCM and the family member at least each week. If the family member does not initiate this weekly contact, the NCM contacts the family by phone.

A quarterly care conference is an ideal time to formally evaluate family, resident, and staff satisfaction with the FIC intervention. Although the length of time for these conferences is often brief, frequent communications provide a critical time for the NCM to solicit feedback and suggestions from family and staff.

EXAMPLES OF PARTNERSHIP ACTIVITIES

⇒ Family member constructs a photo life story book or room bulletin board.

- Photo life story book can be used during visits.
- Family member shares life story book with new staff.
- Staff uses life story book to reminisce with the resident on days when the family does not visit.

⇒ Family member supplies staff with information about the person's life experiences, personality, and accomplishments.

- Family member prepares a tape for all staff to listen to.
- Family member participates in resident care conferences.

⇒ Family member assists in physical care (e.g. bathing, exercise, and grooming).

- Wife assists with bathing on Monday and Thursday evenings.
- Daughter feeds father lunch on Monday, Wednesday and Fridays.
- Son trims mother's fingernails every other week.
- Daughter-in-law monitors physical care by observing cleanliness of resident and reporting any problems to a designated person.

FAMILY AND STAFF PARTNERSHIP ACTIVITIES AGREEMENT

Staff and family have agreed that they are partners in planning, providing, and evaluating care for

_____ (Resident)

Family member(s) will do the following activities (Please include frequency and amount of time for each activity):

_____

_____

_____

_____

Staff will do the following activities (Please include frequency and amount of time for each activity):

_____

_____

_____

_____

Comments and Explanations:

Family Member(s) Signature(s)

_____

_____

Facility Staff Signatures

_____

_____