

## FAMILY CAREGIVER DOMAINS OF PREPAREDNESS

*Updated July 2021*

### Background

The growth rate of older adults living with chronic disease, functional decline, and serious illness is increasing exponentially at a time when availability of both family and professional caregivers is declining. Achieving optimal outcomes for this vulnerable population involves improving the quality of care delivered by families, health professionals, and community programs. By 2050, it is projected that the old age dependency support ratio will increase from 22.8 to 37 in the United States (Vincent & Velkoff, 2010). This dramatic increase suggests that an ever-growing number and percentage of working adults in the US will be involved in family care, posing both personal and financial costs, and potential loss of productivity for employers. (Family Caregiving Institute (FCI), 2018a)

Although caring for a family member can be rewarding and meaningful, it may also be challenging and stressful (Harvath, Lindauer, & Sexson, 2017). Family caregiving encompasses everything from administering medications, to accurately recognizing clinical deterioration requiring urgent intervention, to managing appointments and billing issues, to providing personal assistance with hygiene and routine functional needs, to discussions of preferences for end-of-life care and spiritual needs. Sometimes the need to provide care begins abruptly, for example immediately following a hospital stay; in other situations, the needs develop more insidiously, gradually overwhelming the capacity of families to manage complex care. Early in 2015, AARP conducted a national survey of family caregivers. The survey indicated that many family caregivers struggle with tasks that nurses typically perform, referred to as “medical/nursing tasks.” (Reinhard, Levine, & Samis, 2012) These tasks include management of medications, dressing changes, handling equipment such as oxygen tanks and dealing with incontinence. Family members typically coordinate complex, disconnected and even contradictory clinical direction and information from multiple providers and institutions.

The demands of family caregiving have implications for the mental, physical and financial health of those providing this vital service. Both the caregiver and the person receiving care may face psychological and social challenges such as depression, anxiety and isolation. The stress associated with family caregiving can have a negative effect on caregiver health. These issues may go unrecognized by clinicians and threaten quality of life and well-being. (FCI, 2018a)

As health care providers partner with family caregivers for the benefit of the care recipient, it is important to understand the family caregiver preparedness domains which may assist with assessment, shared decision making, evidence-based interventions, and evaluation.

### Purpose

The **Family Caregiver Domains of Preparedness** are designed to be used by educators, clinicians, and researchers “in the development and application of culturally appropriate educational materials, apps, and other resources. The goal of which is to support family caregivers’ preparedness to provide support that reflects the recipient’s values, preferences, and goals of care based on the activities and responsibilities associated with family caregiving. (FCI, 2018b)

## Definitions

- *Family Caregiving*: the provision of care to individuals with acute, chronic or terminal illnesses or conditions by people who are related by blood, marriage or affinity (i.e., families of choice)
- *Care Recipient*: an individual of any age who is dependent in one or more Instrumental Activities of Daily Living or Activities of Daily Living (IADLs or ADLs) or who needs assistance with complex care tasks as a result of an acute, chronic or terminal illness or condition
- *Family Caregiver*: the person(s) who provide assistance with IADLs, ADLs or complex care tasks to a care recipient who is related by blood, marriage or affinity (i.e., families of choice)
- *Family Caregiver Preparedness*: the caregiver's perceived knowledge, skills, and readiness to enact the multiple domains of the caregiving role, for example, provision of emotional support, organizing in-home support services, household tasks, personal care, health monitoring and coping with the strain of caregiving (Archbold, Stewart, Greenlick, & Harvath, 1990; FCI, 2018b)

### Domain one: Household tasks

This domain focuses on the areas of preparedness to assist the care recipient with household activities.

Assess the family caregiver's preparedness to:

1. Assist with paying bills and managing finances.
2. Manage laundry, prepare meals, perform shopping, and run errands.
3. Perform or coordinate home maintenance activities, including odd jobs.

### Domain two: Personal care

This domain focuses on the areas of preparedness to assist the care recipient with routine personal care activities of daily living, either performing the tasks themselves or coordinating performance of the tasks.

Assess the family caregiver's preparedness to:

1. Assist with bathing, dressing, feeding, grooming and personal hygiene (e.g. oral hygiene, hair care, skin care, nail care).
2. Assist with toileting (e.g. getting to and from the toilet, managing incontinence episodes, maintaining continence).

### Domain three: Mobility

This domain focuses on the areas of preparedness to safely assist the care recipient in moving or transferring positions in a variety of environments.

Assess the family caregiver's preparedness to:

1. Maintain proper and safe body mechanics while assisting the care recipient with safely moving inside and outside the house including stairs, curbs, etc.
2. Assist the care recipient with moving around inside or outside the home.
3. Assist the care recipient with walking.
4. Assist the care recipient with changing position in the bed, chair or wheelchair.
5. Assist the care recipient with safely changing position in the bed, chair or wheelchair.
6. Assist the care recipient to safely transfer in/out of bed, chair wheelchair, toilet and tub/shower.
7. Manage assistive devices such as walkers, canes, or wheelchairs.
8. Assist with appropriate mobility and strengthening exercises.

## Domain four: Health monitoring

This domain focuses on the preparedness to monitor the care recipient's health and appropriately respond to changes in condition.

Assess the family caregiver's preparedness to:

1. Monitor signs, symptoms and response to therapies.
2. Recognize and respond to significant changes in the care recipient's condition, including emergent situations.
3. Use medical devices to monitor patient's condition (e.g., blood pressure cuff, pulse oximeter).
4. Record and report health measurements.

## Domain five: Emotional and social support

This domain focuses on the preparedness to assess and support the emotional and social well-being of the care recipient.

Assess the family caregiver's preparedness to:

1. Provide companionship.
2. Provide support in managing stressful situations.
3. Facilitate engagement in meaningful activities and leisure activities.
4. Help the care recipient adapt to life's challenges.
5. Help the care recipient manage emotional responses.
6. Provide support to manage family conflicts.

## Domain six: Care coordination

This domain focuses on preparedness to coordinate with service providers (health, medical, social, etc.).

Assess the family caregiver's preparedness to:

1. Navigate and communicate within the health care system (doctors, nurses, social workers, pharmacists, and other health care and long-term services and supports).
2. Seek information relevant to the care recipient's needs.
3. Relay information to and from health care providers and the care recipient.
4. Identify the need for additional help/expertise.
5. Locate, arrange, and supervise support services (e.g., nurses, home care aides, home delivered meals, transportation)
6. Make health care appointments (e.g., providers, therapies, testing), order and obtain medications.
7. Collaborate with other family members to meet the care recipient's needs.

## Domain seven: Medical/Nursing tasks

This domain focuses on preparedness to safely perform or coordinate the performance of required medical and nursing tasks to meet the care recipient's needs.

Assess the family caregiver's preparedness to:

1. Support treatment adherence.
2. Administer medications including oral, topical, and injectable.

3. Monitor for and respond appropriately to side effects and adverse effects of medications and other therapies.
4. Assess for therapeutic effects of therapies.
5. Operate and monitor medical equipment (e.g. monitors and pumps).
6. Operate durable medical equipment (e.g. beds and commodes).
7. Provide wound care.
8. Prepare food for special diets, including tube feedings.
9. Use incontinence equipment and supplies (e.g. ostomy, catheters).
10. Manage behavioral symptoms.
11. Manage physical symptoms (e.g. nausea, pain, constipation).
12. Manage hearing or vision deficits.
13. Access training resources.
14. Encourage and support health lifestyle choices.

### **Domain eight: Shared decision making**

This domain focuses on preparedness to participate in shared decision making in ways that reflect the values and preferences of the family in legal, financial, and health care matters.

Assess the family caregiver's preparedness to:

1. Participate in shared decision making.
2. Handle financial and legal matters.
3. Participate in advanced planning.
4. Participate in treatment decisions.
5. Resolve family disagreements about treatment decisions.

### **Domain nine: Caregiver self-care**

This domain focuses on family caregivers' preparedness to engage in activities that support their own mental, emotional, and physical wellbeing.

Assess the family caregiver's preparedness to:

1. Identify and access local (e.g., respite care, support groups) and on-line (e.g. [www.aarp.org/caregiving/](http://www.aarp.org/caregiving/), Alzheimer's Disease and Related Dementias Resource Center) resources to support caregivers
2. Engage in positive stress management techniques.
3. Set priorities.
4. Identify and acknowledge own feelings and stress.
5. Ask for and accept assistance.
6. Engage in healthy behaviors to maintain own physical, mental, and emotional wellbeing.
7. Maintain connection with family and friends.

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*For more information, please contact:*

**Kathryn E. Sexson, Ph.D., A.P.R.N., F.N.P.-B.C.**  
Assistant Clinical Professor  
Family Caregiving Institute  
Betty Irene Moore School of Nursing at UC Davis  
[kesexson@ucdavis.edu](mailto:kesexson@ucdavis.edu)