

## **Organizing A ‘Dementia Care Plan’ For Adults with Intellectual Disability**

Creating a useful ‘dementia care plan’ for persons with intellectual disability can benefit from consideration of several factors. The plan has to address the underlying data noting that dementia is present (either via suspicions or by diagnosis), the nature and expectations stemming from the type of dementia (whether due to Alzheimer’s disease, the result of a infarct, stroke, or other brain damage – vascular dementia – or stemming from another brain condition, such a Lewy body or frontotemporal dementia). A plan needs to consider the housing, living, social, and health needs of the individual both on the short-term and the long-term. In many cases, objective data to address these factors may not be present, but by using this outline, discussions among the family, person involved, and agency personnel can use subjective impressions and best practices in planning to address the individual’s needs.

### **Considerations**

#### **1. Involvement of key people**

- a. Clinical personnel
- b. Support personnel
- c. Key family or significant others

#### **2. Initial diagnostics**

- a. Confirmation of dementia status
  - i. How derived and under what conditions
- b. Determination of cause of dementia
  - i. Consideration of type of dementia
    1. Trajectories and progression
    2. Targeted interventions
- c. Ascertainment of prognosis
  - i. Diagnostician’s recommendations
- d. Consideration of co-morbidities
  - i. Assessment of impact of health-based comorbidities
  - ii. Assessment of pre-existing non-health-based comorbidities
- e. Consideration of individuals understanding of condition
  - i. Psychological status
  - ii. Capability for assisting with care planning
- f. Instrumentation used to record behavior
  - i. Basis of objective information on behavioral changes

1. Instruments used
2. Summary of main findings

### **3. Continued diagnostics**

- a. Plan for periodic re-assessment of condition
  - i. Scope of timing and intervals for re-assessments
- b. Determination of periodic measures for progression of losses
  - i. Agreement of instrumentation to use
    1. Instruments linked to original assessments
    2. Instruments new to behavioral tracking
- c. Assignment of responsibilities for maintaining re-assessments
  - i. Determination who will do the follow-along

### **4. Short-term objectives**

- a. Housing plan
  - i. If remaining at home, assessment information regarding
    1. Physical aspects of family home
      - a. Adaptable for lessening mobility
      - b. Offering personal space
      - c. Permitting wandering
    2. Family capability to provide dementia supports
      - a. Family self-assessment of capability
      - b. Staff assessment of capability
    3. Family preferences/plans for short-term and long-term supports
  - ii. If in out of home, 'aging in place' vs. specialty dementia care housing
    1. Assessment of current living situation
      - a. If in own housing or with spouse or others
        - i. assessment capabilities for mutual supports
        - ii. assessment of housing setting physical capacities
    2. Assessment of agency resources for maintaining 'aging in place'
    3. Assessment of agency resources of potential transfer to specialty housing
- b. Assessment of agency operated housing
  - i. Physical aspects of agency group home or apartment
    1. Adaptable for lessening mobility
    2. Offering personal space
    3. Permitting wandering
  - ii. Staff capability to provide dementia supports
    1. Staff self-assessment of capability
    2. Management assessment of capability
- c. Criteria and targets for transitioning to alternative setting
  - i. Defining what changes or needs will determine initiating transitioning
  - ii. Assessment of preparation and capability of staff at target residences
- d. Activities support plan
  - i. Day supports

- ii. 24/7 supports
- e. Health plan
  - i. Attention to comorbidities
  - ii. Behavior plan for BPSDs
  - iii. Advance directive

**5. Long-term objectives**

- a. Housing plan
  - i. 'Aging in place' vs. specialty dementia care housing
    - 1. Determination of capability to provide advanced dementia and end-of-life care in 'aging in place' setting
    - 2. Determination of level of care capacities of agency's dementia care homes
  - ii. Admission to specialty dementia care housing
    - 1. Ambulatory care supports
    - 2. Non-ambulatory care supports
- b. Activities support plan
  - i. Continued engagement
  - ii. Planning for routines
- c. Health plan
  - i. Medical care for health comorbidities
    - 1. Primary medical conditions
    - 2. Secondary medical conditions
    - 3. Determination of effects of medical conditions on dementia
  - ii. Behavior plan for BPSDs
- d. Advanced dementia care
  - i. Advance directive
  - ii. End-of-life care (hospice, palliative care)

**6. Plan mechanics**

- a. Frequency of review
  - i. Assessment of behavior and capacities
  - ii. Assessment of changes in health status
  - iii. Determination decision-making factors impacting plan
- b. Coding and tracking 'dementia care plan'
  - i. Agency information system in use for tracking
  - ii. Agreement on signal changes indicating need to review plan