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## Chapter 12: Dementia: Detection, Assessment, and Intervention

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## **Chapter 12: Dementia: Detection, Assessment, and Intervention**

### **Sally Pelon**

#### **Abstract**

This chapter considers various forms of dementia as well as the assessment and diagnosis process from a uniquely social work perspective. It also explores various psychosocial and practical interventions that may be utilized by social workers as they support and assist both those with a dementia diagnosis and their loved ones.

**Case Study 12.1**

Jorge Martinez is a 72 year old Hispanic gentleman who resides in his own home with his wife, Rosa. For the past several months, Mrs. Martinez has noted that Jorge has become increasingly irritable and anxious. She describes this irritability and anxiety as most often related to his frustration with forgetting names and misplacing everyday items such as his keys and his wallet. Mrs. Martinez has also noted that Jorge has discontinued activities he previously enjoyed such as meeting his friends for breakfast two mornings each week and reading spy novels. Mrs. Martinez discussed her concerns about her husband with their son, Roberto. Roberto assured Rosa that these issues were likely just age-related changes and that she shouldn't worry. Roberto also questioned if perhaps his father was depressed. Initially, Mrs. Martinez agreed with Roberto, but she continued to be concerned about her husband's symptoms and suggested to him that perhaps he should schedule a visit with their family doctor. Mr. Martinez has thus far refused and has been angry with his wife for 'thinking I'm losing my mind.'

## Case Study 12 .2

Marge Meyer is a 77 year old woman whose husband Paul was diagnosed with dementia three years ago. Mrs. Meyer has been providing care for her husband in their home since the time of his diagnosis, with Mr. Meyer's care needs increasing significantly over the past year as his dementia has progressed. Mrs. Meyer reports that twice in the past month Paul has left their home without her knowledge. A neighbor returned Mr. Meyer home after he was found wandering in the neighborhood. Mrs. Meyer also reports that Paul is becoming increasingly belligerent and difficult to manage. She is worried that Mr. Meyer will get hurt if he continues to get out of the house unattended. She is also concerned that she has been very angry and impatient with Paul and confides that she slapped him once in frustration. Mrs. Meyer feels deeply ashamed and embarrassed about this. She is struggling with what is best for both her husband and herself at this point.

Mr. and Mrs. Meyer have three adult children and seven grandchildren. Their daughters Susan and Sheryl reside out of state but stay in close contact with Mrs. Meyer via telephone and skype. Mr. and Mrs. Meyer's son Kevin lives an hour away from his parents and visits most weekends, either on his own or with his wife, Tonya. The Meyer's children express concern about their mother's ability to continue to provide care for their father as his dementia progresses and they have encouraged her to consider placement in a dementia unit or skilled nursing facility. Mrs. Meyer has toured two nursing homes and a specialized dementia unit for placement of Mr. Meyer but feels incredibly guilty about this. She indicates that she cannot make peace with the idea of 'sending Paul to a home and letting others take care of him-and my kids can't understand this.'

## Understanding Dementia

Dementia is an umbrella term used to describe the progressive loss of cognitive function impacting memory as well as two or more of language, motor activity, recognition, spatial or visual abilities, and judgement ([American Psychiatric Association](#), 2013; [World Health Organization](#) (WHO), 2017). While memory is impaired in all types of dementia, deficiencies in language, motor activity, visual or spatial abilities and judgement typically vary depending on the specific type of dementia (Rabins, Lykesos, & Steele, 2016). The progressive deterioration of mental capacity from previous levels of cognitive functioning distinguishes dementia from cognitive disorders present from birth such as learning or intellectual disabilities (Rabins et al., 2016). The causes of dementia are not fully understood but research has suggested that multiple factors may contribute to its development including age, genetic predisposition, and lifestyle choices such as unhealthy diet, physical inactivity, excessive alcohol consumption, and smoking ([Alzheimer's Association](#), 2018; Harrison-Denning, 2013; Rabins et al., 2016; WHO, 2017).

Dementia is not a universal element of the aging process, however, the prevalence of dementia does increase with age. After the age of 65, the risk for developing dementia doubles approximately every five years. It is estimated that dementia impacts one in 14 individuals over age 65 and one in six people over age 80 ([Alzheimer's Association Facts and Figures](#), 2017). In 2015, an estimated 47 million people worldwide lived with some form of dementia. The number of people with dementia is expected to rise to 82 million by 2030 and to 152 million by 2050 (WHO, 2017). In the United States, approximately 5.5 million people have a diagnosis of Alzheimer's disease or another form of dementia. This number is projected to increase rapidly in

coming years as the population of United States citizens age 65 and older is predicted to nearly double from 48 million to 88 million by 2050 (He, Goodkind, & Kowal, 2015).

The impacts of dementia on society are widespread. Economically, costs of direct medical and social care of those with dementia were estimated to be a staggering 818 billion dollars in 2015 (WHO, 2017). An estimated 70 percent of individuals with dementia are cared for in the home by a family member, most often a spouse or adult daughter and this caregiving places significant physical and emotional demands upon the caregiver (Jenkins, Ginesi, & Keenan, 2015). In addition, care for those with dementia places considerable burden on long-term care systems and has been linked to long-term care staff burnout and turnover (Weinberg, 2003). As the prevalence of dementia continues to increase and its impact persists on all levels of society, it is imperative for social workers to identify various types of dementia, to understand the diagnostic process, and to select and utilize appropriate interventions both for those with dementia as well as their loved ones.

### **Types of Dementia**

Various types of dementia have been noted in research and medical practice. However, the boundaries between different forms of dementia are typically imprecise and mixed forms often coexist (WHO, 2017). The most common forms of dementia are noted as follows.

#### *Alzheimer's Disease.*

Alzheimer's disease is the most common form of dementia, accounting for approximately 70 percent of all dementia cases (WHO, 2017). Alzheimer's disease causes changes in the brain due to abnormal deposits of plaques and tangles within the brain. These plaques and tangles interfere with the normal functioning of brain cells (Denning & Sandilyan, 2015). In the early stages of Alzheimer's disease, memory loss related to recent events and word-finding difficulties

are the most common indicators. As the disease progresses, brain cells die and connections among cells are lost leading to greater memory loss and language difficulties. These changes make everyday activities such as handling money and navigating familiar environments more difficult. Ultimately, symptoms progress to the point that they prohibit the individual from managing self-care activities, completing simple tasks, recognizing familiar people and places, and using language appropriately (Cox, 2007; Denning & Sandilyan, 2015). In addition, it is not uncommon for individuals with Alzheimer's disease to exhibit marked personality changes and to demonstrate non-cognitive symptoms such as aggression, agitation, overactivity, sleep disturbances, and depression. Non-cognitive behavior difficulties impact up to 90 percent of individuals with Alzheimer's disease at some point over the course of their illness (Cox, 2007; Rabins et al., 2016).

For many individuals, an Alzheimer's disease diagnosis is not made until they have manifested symptoms for two to three years (Rabins et al., 2016) and the pace at which symptoms progress from mild to moderate to severe varies from person to person. The duration of Alzheimer's disease is typically eight to 10 years, but can be as brief as two years and as many as 20 years (Alzheimer's Association Facts & Figures, 2017).

Individuals with mild to moderate Alzheimer's disease may benefit from the use of medication to assist with cognitive symptoms such as memory loss, confusion, and difficulty with thinking and reasoning. The [United States Food and Drug Administration](#) has approved two types of medication for Alzheimer's disease. Cholinesterase inhibitors such as Aricept, Exelon, and Razadyne, prevent the breakdown of acetylcholine, a chemical important for learning and memory. Memantine medications such as Namenda, regulate the activity of

glutamate, a chemical involved in information processing (Alzheimer's Association, 2018; Cox, 2007; Harrison-Dening, 2013).

### *Vascular Dementia.*

Vascular dementia is the second most common type of dementia and accounts for approximately 10 percent of dementia cases (WHO, 2017). Vascular dementia is caused by various conditions that block or reduce blood flow to the brain, depriving brain cells of essential oxygen and nutrients. Symptoms may occur abruptly due to sudden-onset conditions such as stroke or they may emerge gradually over time as the result of multiple minor strokes or other conditions that impact smaller vessels leading to cumulative damage (Alzheimer's Association, 2018; Dening & Sandilyan, 2015). A number of risk factors may contribute to vascular dementia including hypertension, hyperlipidemia, diabetes, smoking, and poor diet. Symptoms of this type of dementia vary widely depending upon the part of the brain impacted and the severity of the damage to the affected blood vessels. Unlike Alzheimer's disease, memory loss may or may not be a principle symptom of vascular dementia and is dependent upon the part of the brain impacted by reduced blood flow (Quin, 2013; Rabins, et al., 2016). Following a sudden-onset condition such as a stroke, typically identifiable symptoms such as confusion, disorientation, difficulty speaking, or vision loss may be noted. Gradual onset conditions such as multiple mini strokes typically lead to measured changes such as impaired planning or judgement, uncontrolled laughing or crying, reduced ability to pay attention, diminished capacity to function well in social situations, and difficulty with word finding (Alzheimer's Association, 2018; Dening & Sandilyan, 2015; Rabins et al., 2016).

The United States Food and Drug Administration has not approved any drugs specifically to treat symptoms of vascular dementia, however some research has suggested that certain



medications approved to treat Alzheimer's disease symptoms may offer moderate benefit for those with vascular dementia (Rabins, et al., 2016). Controlling risk factors such as hypertension and diabetes has been demonstrated to be an important treatment strategy in postponing or preventing further cognitive decline (Alzheimer's Association, 2018; Rabins et al., 2016). Similar to other forms of dementia, vascular dementia shortens one's life expectancy. Research has suggested that those with vascular dementia survive approximately three years following diagnosis (Alzheimer's Association Facts & Figures, 2017; Rabins et al., 2016).

#### *Lewy Body Dementia.*

Lewy body dementia is the third most common type of dementia, accounting for just under 10 percent of all dementia cases (Denning & Sandilyan, 2015). Lewy body dementia is a progressive brain disorder in which abnormal deposits of proteins or 'Lewy bodies' build up in areas of the brain that regulate behavior, cognition, and movement (Quin, 2013; Rabins et al., 2016). Lewy body dementia presents with a range of symptoms including memory loss similar to Alzheimer's disease. Other features of this type of dementia mirror Parkinson's disease including gait abnormalities and reduced facial expression. In addition, vivid visual hallucinations, distinct fluctuations in level of consciousness, and disturbed sleep are characteristic features of Lewy body dementia (Denning & Sandilyan, 2015; [Lewy Body Dementia Association](#), 2018; Rabins et al., 2016).

There are few known risk factors for Lewy body dementia other than advanced age and sex. Men are more likely than women to be diagnosed with Lewy body dementia as are individuals over age 60 (Lewy Body Dementia Association, 2018; Rabins et al., 2016). Medications may be used to treat the various symptoms of Lewy body dementia. Cholinesterase inhibitors such as Aricept, Exelon, and Razadyne used with Alzheimer's disease have been

shown to be helpful with memory function and psychosis related to this disorder. Dopaminergic medications such as Levodopa and Duopa, often prescribed for those with Parkinson's disease, may be helpful with motor function deficits. However, traditional antipsychotic medications such as Haldol, Prolixin, and Mellaril are contraindicated for psychosis associated with Lewy body dementia as these have been demonstrated to exacerbate psychotic symptoms (Lewy Body Dementia Association, 2018; Rabins et al., 2016; Zupancic, Mahajan, & Handa, 2011).

### *Frontotemporal Dementia.*

Frontotemporal dementia is a comparatively rare form of dementia. This type of dementia is a broad term that describes a range of conditions that impact the front portions of the brain responsible for planning, language, and emotion. Type and clinical features of frontotemporal dementia vary depending on which part of the frontal or temporal lobe is most impacted (Jenkins et al., 2015; Rabins et al., 2016). Approximately half of frontotemporal cases present with behavioral changes that can be quite profound and include lack of inhibitions, lack of empathy, overeating, and assumption of inflexible routines due to the lack of mental flexibility and difficulty planning. Roughly half of frontotemporal dementia cases also present with speech and language deficits such as losing meaning of words and concepts and difficulty producing speech (Denning & Sandilyan, 2015; Rabins et al., 2016).

There are no known risk factors for frontotemporal dementia other than family history. This type of dementia is inherited in approximately 30 percent of diagnosed cases (Alzheimer's Association, 2018). There are no specific treatments available for frontotemporal dementia. However, psychotropic medications may be indicated to decrease irritability, agitation, and/or depression associated with the disease. The pace of decline with this disease varies from person

to person with wide-ranging duration from two to 20 years ([Association for Frontotemporal Degeneration](#), 2018).

#### *Other Dementias.*

There are a number of other less common diseases that may cause dementia or have dementia as one of a number of other symptoms. These include Parkinson's disease, Huntington's disease, Creutzfeldt-Jacob disease, Korsakoff's syndrome, and Multiple Sclerosis (Denning & Sandilyan, 2015; Jenkins et al., 2015; Quin, 2013; Rabins et al., 2016).

#### **Assessment and Diagnosis**

In many cases, recognition that an assessment for dementia is needed comes from a family member rather than from the individual experiencing symptoms (Rabins et al., 2016). Typically, as a spouse or adult child begins to observe memory or functional changes in their loved one, they ascribe this to the 'normal' aging process, as noted in Case Study 1 by Mr. Martinez's son, Roberto. It is often not until the family member observes indisputable forgetfulness, language difficulties, problems functioning and/or personality changes that she or he encourages or facilitates an assessment with a physician. Consequently, diagnosis of dementia is often quite delayed (Cox, 2007; Quin, 2013; Rabins et al., 2016). In addition, it is not uncommon for family members to pursue a dementia evaluation for their loved one only after a crisis such as having a car accident, forgetting to pay bills, or getting lost in familiar surroundings (Quin, 2013; Rabins et al., 2016).

Diagnosis of any form of dementia is difficult as there is no diagnostic test or procedure to explicitly determine that an individual has dementia (Cox, 2007; Quin, 2013; Rabins et al., 2016). In addition, dementia symptoms may initially be misidentified as other disorders. Social withdrawal and reduced interest and initiative that can accompany mild to moderate dementia

may be misdiagnosed as depression while inappropriate behaviors may be misidentified as psychosis (Babbington, 2008). Diagnosis of the presence or absence of dementia as well as the specific type of dementia is achieved through a variety of assessment techniques and is completed by various medical professionals, including social workers.

A full medical and family history is an important piece of dementia diagnosis (Quin, 2013; Rabins et al., 2016). It is necessary to accurately and fastidiously identify the presentation, timing, and progression of dementia symptoms. In addition, it is important to gather information regarding co-occurring symptoms as well as history of prior physical and psychological issues. Gathering the medical and family history can be a challenge as the individual her or himself is typically unable to provide much of this information. (Quin, 2013; Rabins et al, 2016). Consequently, medical and family history is often accomplished through in-depth interviews with family members.

Assessment instruments are available that may complement medical and family history in diagnosing dementia. Common screening tools include the [AD8 Dementia Screening Questionnaire](#) and the [General Practitioner Assessment of Cognition](#) (Rabins et al., 2016). Additional standardized tests that may be helpful during the diagnosis phase are the [Mini Mental Status Exam \(MMSE\)](#) or the [Montreal Cognitive Assessment \(MOCA\)](#) which use a series of questions and activities to generate a score indicating mild, moderate or severe cognitive impairment (Jenkins et al., 2015). Also beneficial are standardized tests that measure functional status and the ability to complete both basic activities of daily living (ADLs) such as bathing, toileting, getting in and out of bed, and dressing as well instrumental activities of daily living (IADLs) such as handling money, shopping, taking medications, and cooking. Such tests include the [OARS Multidimensional Functional Assessment Questionnaire](#), the [Functional Activities](#)

[Questionnaire](#), and the [Lawton and Brody IDAL and Physical Self Maintenance Scale](#) (Rabins et al., 2016).

In addition to a complete physical history and administration of neuropsychological tests, a thorough physical examination is necessary in diagnosing dementia. Blood and urine analysis and brain imaging may be helpful as well in order to rule out other potential causes of dementia symptoms such as tumor or certain vitamin deficiencies (Harrison-Dening, 2013; Quin, 2013; Rabins et al., 2016).

### **Early Diagnosis**

There are a number of benefits to early detection and diagnosis of dementia. Family members who recognize that their loved one is indeed impaired and understand her or his deficits in judgement and changes in behavior and personality related to the diagnosis, as Mrs. Martinez in Case Study 1 has, may be more likely to pursue necessary supervision and support in order to avert in-home accidents, injuries from falls, or getting lost. Early detection and diagnosis is important as appropriate medications or other treatments may be initiated and response to these may improve or delay progression of cognitive decline in some types of dementia. Psychological and/or behavior disturbances related to the dementia such as delusions, aggression, or depression are able to be managed more appropriately and successfully as well. Early detection and diagnosis also allows more time for the individual and his or her loved ones to plan for medical, financial, and legal matters and care choices to manage the consequences of dementia as it progresses. (Quin, 2013; Rabins et al., 2016). Finally, early detection and diagnosis can provide the individual with opportunity to make the most of current abilities and time with loved ones (Jenkins et al, 2015). Social workers assist with early detection when they encounter clients who may be demonstrating cognitive decline. Gently opening conversations regarding observed

deficits and behaviors with the individual and/or her or his family members may be helpful.

## **Dementia Care**

As cognitive and functional impacts of dementia progress, patients require increasing levels of support, supervision, and care. Consequently, family members are called on to make complex and difficult care decisions for their loved one, such as Mrs. Meyer is struggling with in Case Study 2.

### *Caregiving Options*

As noted previously, approximately 70 percent of those with dementia are cared for in the home by a loved one. In 2016, these unpaid family caregivers provided an estimated 18.2 billion hours of assistance to an individual with a dementia diagnosis (Alzheimer's Association, Facts & Figures, 2017). There are a number of reasons that family members choose to provide care to their loved one with dementia. These reasons include the desire to maintain the individual at home in familiar surroundings, the perceived obligation as a spouse or adult child to provide care, and proximity to the loved one with dementia (Alzheimer's Association Facts & Figures, 2017). Family caregivers of those with dementia are typically responsible to ensure patient safety and meaningful activity, to assist with mobility and activities of daily living, to ensure medication compliance, and to manage finances (Cox, 2007; Rabins et al., 2016).

As dementia progresses and cognitive and functional abilities decline, care needs may extend beyond the capacity of the family to provide care to the individual in the home. In other cases, the person with dementia may not have family members or friends who are able to provide necessary care due to distance or other family or work obligations. In these situations, residential care may be required. Over the past several years, residential care choices have expanded beyond the traditional skilled nursing home option. Out-of-home care options now include

specialized dementia units that provide care tailored to the needs of those with dementia, assisted living communities, and in the final stages of dementia, hospice care facilities (Cox, 2007; Rahman, 2015).

It is unclear whether residential care or in-home care is more suitable for persons with dementia as there are benefits and drawbacks to both and suitability may depend upon individual circumstances. (Cox, 2007; Rabins et al., 2016). Residential facilities are able to provide consistent supervision and medical and medication oversight by trained staff that is typically not available in the home. In addition, residential facilities generally offer increased social interaction and socialization activities that may be absent for those individuals being cared for in the home (Cox, 2007). However, residential facilities are typically less able to provide the personalized and individualized care that those with dementia may receive from a loved one in the home setting as Mr. Meyer is receiving from his wife in Case Study 2. In addition, facility staff lack emotional connectedness to and history with the person with dementia and this has the potential to negatively impact care (Cox, 2007). Understaffing in facilities can also result in decreased quality of care to residents with dementia (Cox, 2007; Rabins et al., 2016). Finally, the cost of care in residential facilities is substantial and may be prohibitive for some families. In 2017, the average monthly cost for assisted living facilities was \$3,750 and the average monthly cost for a semi-private room in a skilled nursing facility was \$7,148 ([Genworth Financial](#), 2017).

### **Social Work Interventions**

Dementia has been described as a family disease; regardless of type, dementia impacts not just the individual diagnosed with dementia but the entire family system (Cox, 2007; Jenkins et al., 2015; McGovern, 2015). Consequently, both those diagnosed with dementia as well as their loved ones require support and assistance as they navigate many changes and challenges

throughout the course of the disease. Social workers contribute a unique set of skills and professional values that are helpful in providing care to those with dementia and their loved ones. Social workers' person-in-environment perspective allows them to understand and work with and through the environmental contexts in which individuals live and act. In addition, social workers' training in human behavior in the social environment, human diversity, communication and counseling skills ([Council on Social Work Education \[CSWE\] Educational Policy and Accreditation Standards](#), 2015) equips them to assess and address the psychosocial needs of those with dementia and their families. Finally, social workers' training in and understanding of macro systems prepares them to intervene and advocate with agencies and other systems on behalf of those with dementia and their families (Cox, 2007).

#### *Interventions with Those with Dementia*

The receipt of a dementia diagnosis is typically difficult. While there may be some relief in having an explanation for symptoms, it is common for those receiving a dementia diagnosis to experience shock, anger, sadness, and/or hopelessness (Jenkins et al., 2015). Feelings of loss and grief are expected, particularly in the early stages of dementia when the individual has awareness of her or his present deficits and future decline (Cox, 2013). In these earlier stages, social workers may provide individual counseling services focused on increasing adjustment to the diagnosis and coping with the challenges of the illness as it unfolds (Harrison-Dening, 2016). Social workers normalize feelings of sadness, anger, and fear and allow opportunity to safely express these feelings. Social workers may also engage those with dementia in life review activities that trigger fond memories and allow them to recall significant and meaningful life events (Harrison-Dening, 2016). Social workers may facilitate [cognitive stimulation therapy](#) through structured group sessions aimed at stimulating thinking and social engagement (Spector,



Thorgrimsen, Woods & Orrell, 2005). In addition, social workers employ and encourage others to utilize appropriate communication techniques with those with dementia. These include using the individual's chosen name, including rather than excluding the individual in conversation, using a warm and caring voice, maintaining appropriate eye contact, and reducing external distractions (Harrison-Dening, 2015; Jenkins et al., 2015; Rabins et al., 2016).

In the early to middle stages of dementia, social workers may utilize and educate loved ones to employ various interaction techniques with those with dementia. Two such techniques are reality orientation strategies and validation strategies. [Reality orientation](#) assists persons with dementia to remain oriented to current reality and to reinforce their own identity as well as their relationships with others. Family members and professional caregivers seek to naturally incorporate orienting information into all interactions by using the individual's name, using their own name, and naming the current day, time, and/or place (Jenkins et al., 2015). There are however, conversations and situations when reality orientation may be contraindicated. If, for example, the person with dementia asks for a loved one who has died, it can be cruel and insensitive to repeatedly remind him or her of this loss. In general, if orienting the individual causes emotional distress, validation techniques may be more appropriate (Jenkins et al., 2015).

[Validation techniques](#) are based on the belief that those with dementia increasingly experience their reality in terms of emotional and historical events and have difficulty relating to current realities, particularly in the middle to late stages of dementia (Fell & de Klerk-Rubin, 2002). Validation techniques focus on the emotional rather than the factual content of interactions and require that family members and professional caregivers acknowledge and accept the individual's statements and perception of reality, even though they may be neither true nor real. This method of communicating with those with dementia often reduces distress and

prevents argumentative and agitated behaviors (Fell & de Klerk-Rubin 2002; Jenkins et al., 2015).

### *Interventions with Family Members*

Family members of those with dementia face many challenges as they seek to provide appropriate support and care to their loved one while also working through their own feelings and losses related to the diagnosis. Social workers provide necessary support, education, and resources to family members and caregivers as they meet these challenges.

Family members often struggle with the gradual and progressive loss of the loved one they once knew. Jenkins and colleagues (2015) have described this experience as a 'living bereavement' in which the individual with dementia is physically present but cognitively and emotionally absent. Feelings of anger, frustration, guilt, and sadness are expected to varying degrees throughout the course of the illness as family members experience the progressive loss of companionship, support, shared activities, intimacy, and reciprocal relationship (Jenkins et al., 2015; McGovern 2015). Social workers provide counseling and support to family members focused on validating, expressing, and working through their feelings and coming to terms with their loved one's progressive limitations (Rabins et al., 2016). Social workers may also draw upon the strengths perspective that suggests that everyone possesses resources that can nurture growth and contentment, regardless situation or condition (Saleeby, 2013). This perspective can assist family members to emphasize the present and to focus on what remains in their loved one and in their shared relationship rather than on what is lost. This may be helpful in promoting more positive feelings and improving quality of life both for the individual with dementia as well as the family (McGovern, 2015).

In addition to the emotional and relational complexities faced by family members of those with dementia, practical issues of supervision, support, and care must be addressed. These decisions also must be reassessed and modified as the individual's cognitive and functional abilities decline over the course of their illness. Social workers provide a number of interventions to assist families as they wrestle with these weighty decisions.

Social workers educate families regarding anticipated cognitive and functional decline as the individual's dementia progresses and provide hard copy and/or web-based information to assist families in understanding their loved one's specific type of dementia (Harrison-Dening, 2016; Rabins et al., 2016). Social workers discuss with and assist families to make informed care decisions that balance supervision and safety needs with preservation of the individual's dignity and safe and reasonable independence (Rabins et al., 2001). Social workers also provide information regarding care options including family-provided care, paid in-home caregivers and facility placement alternatives (Manthorpe & Iliffe, 2005). In addition, they assist the family in weighing the benefits and burdens of various care options and in making a plan for care based on their values, cultural preferences, and knowledge of patient wishes (Rabins et al., 2016). If there is disagreement among family members about the preferred and most suitable care option for the individual, social workers organize family meetings to facilitate discussion and decision-making (Harrison-Dening, 2016; Rabins et al., 2016). Finally, social workers discuss with family members and assist them in completing legal, financial, and advance directives paperwork, as needed (Harrison-Dening, 2016; Manthorpe & Iliffe, 2005).

Family members who provide direct care to their loved one with dementia in the home may experience conflicting sentiments and reactions, as experienced by Mrs. Meyer in Case Study 2. On one hand, they may feel a sense of purpose, gratification, and mastery in their

caregiving (Cheng, Mak, Lau, Ng, & Lam, 2016). On the other hand they may feel overwhelmed, isolated, alone, and angry. Providing care for an individual with dementia is physically and emotionally draining, particularly as the individual's cognitive and functional abilities decline and length of caregiving increases (Cox, 2007; Jenkins et al., 2015).

Approximately 30 to 40 percent of family caregivers of those with dementia struggle with depression and the risk for depression increases as the individual's cognitive deficits increase (Mausbach, Chattillion, Roepke, Patterson, & Grant, 2013; Sallim, Sayampanathan, Cuttilan, & Chun-Man Ho, 2015). In addition, anxiety is prevalent among family caregivers of those with dementia (Alzheimer's Association, 2018). Along with these mental health concerns, family caregivers are more likely than their non-caregiving counterparts to develop acute illness and other health problems as well as to suffer injury while providing care (Jenkins et al., 2015; McGovern, 2015).

Social workers intervene in various ways with family caregivers to ensure and promote their physical and mental wellbeing. Social workers encourage family caregivers to establish daily routines for care and simple, meaningful activities that can be comforting for both the individual with dementia as well as the family caregiver (Rabins et al., 2016). Social workers monitor family caregivers for signs of depression, anxiety, and stress and provide appropriate counseling services related to these issues (Cox, 2007; Jenkins et al., 2015). They discuss and encourage self-care and relaxation techniques and encourage discussion with physicians regarding possible pharmacological treatment for depression and/or anxiety (Cox, 2007; Jenkins et al., 2015). Social workers promote breaks in caregiving responsibilities and facilitate respite opportunities through family members or friends, paid caregivers, adult day care programs, or temporary facility placement (Jenkins et al., 2015; Rabins et al., 2016). Social workers also

connect caregivers with appropriate community resources such as caregiver support groups or online caregiver communities (Cox, 2007; Rabins et al., 2016).

At times and for various reasons, family caregivers make the decision to move their loved one from home-based care to facility care. This is often due to caregiver illness, injury, or stress or patient care needs or problematic behaviors that extend beyond what the family caregiver is able to safely manage (Rabins et al., 2016). Whatever the reason, family caregivers who eventually place their loved one in a facility often struggle with feelings of guilt and failure (Rabins et al., 2016). In these situations, social workers offer support and counseling to validate the caregiver's decision to pursue placement and to work through their feelings about the need for placement. In addition, social workers assist family caregivers in locating an appropriate placement and transitioning the patient from home to the facility. Finally, social workers encourage and facilitate family involvement with their loved one at the facility to improve her or his adjustment and quality of life (Cox, 2007).

### **Chapter Summary**

Dementia and its progressive cognitive and functional limitations create distinctive and complex challenges both for those diagnosed with any form of this disease and their loved ones and caregivers. Early diagnosis and intervention is important in order to provide time and opportunity for planning for care, supervision, and support as well as to initiate medications that may assist in slowing progression of the disease or mitigating associated emotional and psychological symptoms. Social workers provide a variety of interventions and resources to assist both those with dementia and their loved ones in coping successfully with the many challenges associated with dementia diagnoses.

## Chapter Review Questions

1. What is the most common form of dementia?
  - a. Vascular Dementia
  - b. Lewy Body Dementia
  - c. Alzheimer's Disease
  - d. Frontotemporal Dementia
2. What percent of those with dementia are cared for in their own homes by a loved one?
  - a. 40 percent
  - b. 50 percent
  - c. 60 percent
  - d. 70 percent
3. An intervention that may be facilitated by social workers includes structured group sessions aimed at stimulating thinking and social engagement of those with dementia is called
  - a. Cognitive Stimulation Therapy
  - b. Validation Therapy
  - c. Reality Orientation
  - d. Cognitive Behavior Therapy
4. Review the social work interventions discussed in this chapter. What interventions do you believe would be most helpful and appropriate for Mr. and Mrs. Martinez in Case Study 1? For Mr. and Mrs. Meyer in Case Study 2?
5. What do you believe would be the most difficult aspect of learning of a loved one's dementia diagnosis? Of providing care to a loved one with dementia? Why?

## Additional Exercises

1. Explore the websites of the various dementia organizations discussed in this chapter. What additional information about the different types of dementia can you glean from these websites?
2. Investigate the many cognitive assessment tools discussed in this chapter that are helpful in the diagnosis of dementia.
3. Take the WebMD Alzheimer's Myths and Facts Quiz and discuss your results with a friend or colleague.  
<https://www.webmd.com/alzheimers/rm-quiz-alzheimers-myths-facts>

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