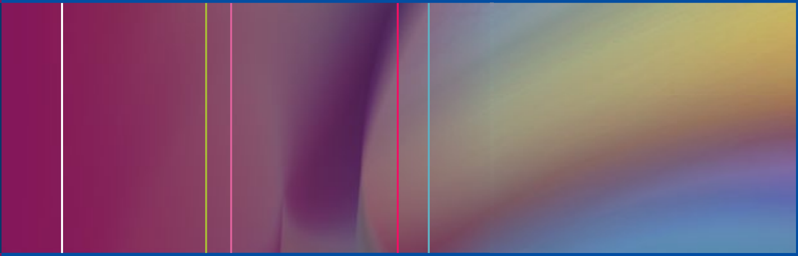
Maureen Nash · Sarah Foidel
Editors



Neurocognitive Behavioral Disorders

An Interdisciplinary Approach to Patient-Centered Care

Springer

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Preface

A Call to Act

> We must learn to regard people less in the light of what they do or omit to do, and more in the light of what they suffer. [Dietrich Bonhoeffer, *Letters and Papers from Prison*.]

Simply stated, persons living with dementia suffer. This textbook serves as a call to recognize and address the suffering inherent in dementia. Dementia, now referred to as major neurocognitive disorder (MNCD) in the 2013 edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5), is conceptualized as a cognitive disorder with concomitant functional impairment. Although behavioral disturbance is briefly mentioned, there is little emphasis on neuropsychiatric symptoms in the DSM-5. The authors of this book posit that there is a practical, clinical, and moral imperative to remedy the neglect of the impairments that those living with dementia experience, namely, neuropsychiatric symptoms (NPS) and the suffering caused by NPS. Suffering can be decreased only when it is recognized.

We note that Frau Auguste, the first person diagnosed with what is now known as Alzheimer's disease, came to the attention of Dr. Alzheimer in the early 1900s due to persecutory delusions, hallucinations, screaming, and other neuropsychiatric symptoms (Maurer 1997). Similarly, it is the suffering due to NPS that often brings persons living with dementia into the health-care system. A large cohort study in Europe showed that those who were later diagnosed with dementia were significantly more likely to be treated with antipsychotic, antidepressant, anxiolytic, and hypnotic medications months or even years prior to their dementia diagnosis (Martinez, 2013). A path to address and minimize these symptoms, inflicted on both the person living with dementia and the individuals that love and care for them, is the focus of our book. The authors offer a roadmap for the assessment and treatment of those with MNCD.

The philosophical notion of being present – human to human – and understanding another's experience is central to caring for those with dementia. In this book, we travel to the depths of NPS and its impact on persons living with dementia, as well as those of us who care about and for them. We propose a paradigm shift to an interdisciplinary team model that incorporates a deep understanding of cognitive domains and objective testing of actual functional abilities. We encourage interdisciplinary teams to truly understand the areas of personal strengths contained in each person living with dementia. By understanding these strengths, we posit that one can truly develop a strength-based care plan. Person-centered care is embodied when we accompany the sufferer on the journey; in fact, the journey itself creates meaning from the experience (Rose and Armstrong 2003).

The fundamental philosophy underlying person-centered care is to create a human relationship between the person living with dementia or other MNCD and those of us who care about and for them. The personal, rather than clinical, relationship is central to creating this paradigm shift. We strive to intervene in the lives of those living with MNCD by providing education and practical information for providers and caregivers in a compassionate and pragmatic manner.

Dementia includes a wide spectrum of illnesses and symptoms related to cognitive dysfunction, behavioral symptoms, and functional deficits. We encourage providers to routinely incorporate assessment and treatment of NPS when working with those living with dementia. We therefore outline the NPS considerations that accompany specific types of dementia in the context of functional abilities. With this approach, we promote positive outcomes for those living with dementia and hope to mitigate suffering.

Through the use of a shared decision-making model, we are able to transform a person-centered model into a truly person-directed model. Early attention to advanced care planning is essential. Teaching the person living with dementia and their family about the trajectory common to their specific type of dementia allows for realistic planning. Incorporating palliative care at the time of diagnosis and encouraging open conversations between the person living with dementia and their loved ones help to minimize suffering throughout the disease.

This book also focuses on behavior as communication. Behaviors are ubiquitous and normal and serve as a principal mode of communication. In fact, behaviors can become the only mode of communication for those who have trouble understanding or using language. We strive to demystify behaviors by recognizing and characterizing them in terms of underlying emotional expression. By doing so, we are able to interpret the message that is being communicated, thus strengthening the promotion of person-centered care.

In this book, we also address the social justice struggles inherent in caring for this vulnerable population. We look at ethnic and racial discrepancies that lead to inequitable distribution of pain management modalities. We raise questions about the conflicting standards of care for individuals living with both a dementia and a concurrent psychiatric illness. We strongly advocate for treatment of psychiatric illness, even in the context of potential conflict with institutional or regulatory guidelines, specifically in regard to well-meaning efforts for gradual dose reduction (GDR) of psychotropic medications in care facilities that may cause unintended consequences for individuals with concurrent psychiatric illness. We advocate that individuals with preexisting psychiatric illness deserve to have their illness treated without exposure to risk of the suffering that accompanies decompensation simply because they also have dementia.

Finally, we provide solid and clinically useful strength-based care plans from a person-directed viewpoint. We give examples of ways to teach caregivers how to create meaningful activities by focusing on the journey. Viewing the process as a road trip without a destination enables the person with dementia, as well as those that care for them, to discover the scenery along the way.

With that said, we invite you to use this book as your own Call to Action on behalf of this vulnerable population and use it to instill hope for persons living with dementia as well as those of us that love and care for them.

> Human progress is neither automatic nor inevitable... Every step toward the goal of justice requires sacrifice, suffering, and struggle; the tireless exertions and passionate concern of dedicated individuals. [Martin Luther King, Jr.]

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Contents

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Chapter 1
Neuropsychiatric Symptoms Are a Core Feature of Neurocognitive Disorders

Maureen C. Nash

Dementia as a Cognitive, Behavioral, and Functional Disorder

Dementia is described as a syndrome affecting cognition (memory and thinking), behaviors, and the ability to perform activities by the World Health Organization (WHO) [19]. WHO published a 2012 report outlining challenges due to dementia which impact the physical, psychiatric, and economic well-being of those with dementia, their families, and society. The report was part of a worldwide campaign to bring awareness and attention to dementia as well as hopes of reducing stigma and barriers to diagnosis and care for those living with dementia. The American Psychiatric Association (APA) last updated its *Diagnostic and Statistical Manual* to a fifth version (DSM-5) in 2013. APA now refers to the progressive neurodegenerative diseases that most people refer to as dementia with the phrase major neurocognitive disorders (MNCD). The central features of MNCD, as described in the

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DSM-5, are cognitive deficits and functional impairment in a person's ability to perform instrumental activities of daily living and activities of daily living. One challenge with the way DSM-5 conceptualizes neurocognitive disorders is the emphasis on cognition with some emphasis on functional impairment rather than the WHO triad of cognition, behavior, and function. Of the 53 pages in the DSM-5 devoted to neurocognitive disorders, less than one page addresses the definition and occurrence of behavioral disturbance. The WHO description of dementia is more consistent with the common view of dementia as well as how most living with dementia come to clinical attention.

Currently, there are no disease-modifying treatments for the leading types of dementia including Alzheimer's disease, Lewy body dementia, and frontotemporal dementia. There are no current treatments that reverse cognitive decline in any neurodegenerative disease. There are some pharmacological and behavioral interventions that appear to possibly slow the rate of functional decline in certain types of dementia. This evidence is not robust, meaning that there are a few suggestive studies but not a significant base of evidence [9, 13, 14].

Neuropsychiatric symptoms (NPS) are universal in dementia. The Cache County study followed a group of people with dementia longitudinally for 5 years and found that 97% of those with dementia experienced at least one NPS [16]. NPS, also referred to as behavioral and psychological symptoms of dementia (BPSD), are notable in two ways: they are the symptoms that cause caregivers and people living with dementia the most quality of life impairment, and they are the only symptoms of dementia currently modifiable on a reliable basis [5, 11]. Note that even the first person diagnosed with what is now known as Alzheimer's Disease, Frau A, came to the attention of Dr. Alzheimer in the early 1900s due to her severe NPS.

> Frau A., the first person known to have Alzheimer's disease, came to medical attention due to persecutory delusions, hallucinations, screaming, and other NPS. [8]

Dementia Transitions to MNCD

Major neurocognitive disorder (MNCD) as a category in the DSM-5 describes degenerative dementia syndromes and other cognitive disorders. MNCD involves a complex combination of neuropsychiatric signs and symptoms. One reason the APA transitioned from dementia to major neurocognitive disorder involved differentiating between the degenerative diseases, particularly those that include most dementias, from other conditions that may be more static. Earlier detection of disease is another. Earlier and more accurate diagnoses will improve the chance of discovering disease-modifying treatments as well as identifying those who will benefit from treatment. Dementia is not a single entity. Dementia is a general phrase and represents several different syndromes. In both the medical literature, newspaper articles, and everyday speech, people frequently use the word dementia as if they were referring to one specific disease. This has likely led to some of the challenges in studying people who have a dementing illness. If the people being studied have different illnesses, yet are all placed in the same category, it can be difficult to differentiate what is helpful for some illnesses and not for others. Additionally, there is hope that changing the term from dementia to neurocognitive disorder will help address the stigma associated with the word dementia. In this chapter, the term dementia will be used when speaking about those specific major neurocognitive disorders associated with degenerative brain diseases; see Table 1.1 for those MNCD commonly thought of as diseases causing dementia. When a dementia is being referenced, the actual name of that disease will be used.

Neuropsychiatric Symptoms

As dementia advances, NPSs appear to become intrinsic to the neurodegenerative disease. It is quoted that anywhere from 80% to 90% of those with a degenerative dementia

TABLE 1.1 MNCD in DSM-5 that are considered degenerative dementias

Major neurocognitive disorders considered degenerative dementias
Alzheimer's disease
Vascular neurocognitive disorder
Neurocognitive disorder with Lewy bodies
Neurocognitive disorder due to Parkinson's disease
Frontotemporal neurocognitive disorder
Neurocognitive disorder due to Huntington's disease
Neurocognitive disorder due to prion disease

have behavioral and psychological symptoms of dementia (BPSD) also known as NPS over the course of their disease though one of the longest longitudinal studies referenced above found the actual percentage was nearly 100%. Behavior, by definition, is a normal and necessary part of life. This is one reason the authors of this text choose to describe BPSD as NPS. The NPS of dementia drive many if not most of the quality of life impairments, need for placement outside the home as well as caregiver distress [3]. Nearly all studies have shown the very high prevalence of NPS in those with dementia [20]. Some neuropsychiatric symptoms are best approached with behavioral and environmental interventions, while others are most safely approached using medications. There is a noteworthy evidence base supporting the use of specific medications in the hands of well-trained geriatric psychiatrists, behavioral neurologists, or others who specialize in that area [6, 10, 11, 12, 15]. Behavioral interventions, functional assessments, and strength-based care planning should be used with everyone. Although this text will not review in-depth specific medications used in treating neuropsychiatric symptoms, the reader may find the list outlined in Table 1.2 useful in knowing where the addition of medications may be helpful in decreasing suffering and where there may be little efficacy in using medications.

TABLE 1.2 Neuropsychiatric symptoms and responsiveness to medications

Neuropsychiatric symptoms (NPS)	
NPS not usually responsive to treatment with medications	**NPS usually responsive to treatment with medications**
Repetitive questions	Paranoia and delusions
Anxiety about memory loss or other deficits	Hallucinations
Psychomotor agitation *unless related to pain*	Pain
Sleep problems	Aggression
Calling out *unless related to pain*	Anxiety disorders – not the symptom of anxiety as a reaction to having cognitive impairment
Ambulating or wandering – otherwise generally known as walking	Major depressive episode – not grief, sadness, or apathy
Appetite problems	

Specific NPS include psychotic symptoms (paranoia, delusions especially persecutory delusions, hallucinations especially visual hallucinations, mood symptoms such as depression and elation, anxiety, agitation, anger outbursts, combativeness, resistiveness to cares such as bathing and feeding, disruptive motor or vocal activity, sleep disturbance (including insomnia, hypersomnia, rapid eye movement sleep behavior disorder, and circadian rhythm disturbance), apathy, wandering, disinhibition, hyperphagia, hoarding [1]). Other NPS include excessive motor activity such as pacing in the hall or repetitively picking something up and carrying it around, irritability, mood lability, and appetite disruption.

Dementia as a Leading Health Concern

According to the United Nations and its world population prospects report from 2017, there are an estimated 962 million people aged 60 and above [17]. Alzheimer's disease is by far the most common type of dementia. Age is the largest risk factor for developing Alzheimer's disease. Thus, we are facing a rapid increase in the number of people living with Alzheimer's disease. Newspaper headlines, medical journals, and magazines contain language such as the following: a "tsunami" or "tidal wave" of people with dementia is heading toward our shores. Even the most optimistic voices that predict a decline in the rate of new dementia cases continue to predict that the number of people developing dementia in any given year will remain roughly the same [18]. The Cognitive Dysfunction and Aging Study is a multicenter population-based study that sampled two English/Welsh groups in two different time periods. They report a 20% drop in incidence in dementia though there was no change in the actual number of new cases because:

> "Dementia continues to be a topic of major international interest with successive reports suggesting large increases throughout the world in the next decades. Following governmental concern and the 2013 G8 summit, the World Dementia Council has been established to facilitate greater attention both in research to support reduction of risk, better diagnosis and treatments, and support for those at risk of, and with, the dementia syndrome. [7, p. 2]"

Beyond the Medical Model to Person-Centered Care

We have come to define dementia clinically by a group of deficits and the loss of functioning. This corresponds to the medical model of diagnosis and allows us to name illnesses in a way that allows clear communication and research. Because we have a clear definition when people talk about Alzheimer's disease, we are likely to be talking about the same illness. This also applies to Lewy body dementia and many other types of dementia. Knowledge of the specific type of dementia a person has is essential to assist persons with dementia, their families, and caregivers, so they will know what to expect in the present and the future. This is most true in the early and middle stages of these diseases. Once someone has very advanced dementia, it becomes difficult or impossible to accurately differentiate the type of dementia.

Despite the utility of the medical model for diagnosis, the authors of this text believe that the medical model is not the best paradigm to use for care planning with those experiencing a MNCD. The authors here propose a new model based upon recognition and treatment of neuropsychiatric symptoms using functional assessments both to define assets as well as deficits. The functional strengths that a person has are what allow us to design the most respectful and comprehensive assessment and plan. Periodic reassessment of a person's ability to function enables people living with dementia to do as much for themselves as they can without unrealistically expecting them to do things they are unable to do. The team's goal is to use a strength-based functional framework for understanding behavior and assisting people by focusing on the highest quality of life possible. The team always includes the person with dementia, their family, as well as professional staff and personal caregivers.

By far the most common type of dementia is Alzheimer's disease. It is estimated that between 60% and 90% of people with major neurocognitive disorder have at least a component of Alzheimer's disease. Dementia due to Lewy body disease, Parkinson's disease dementia, and frontotemporal dementias are the next most common types of dementia [1]. One key to understanding neurocognitive disorders is that these are acquired over life rather than being the lack of development. Because these illnesses are defined by loss of functioning, we must attain that functioning first. Cognitive deficits are present in all serious mental illness. For example, schizophrenia, bipolar disorder, and major depressive disorder all involve impairments in executive functioning. The presence of significant cognitive impairment in many mental illnesses is often overlooked but is likely the main reason serious mental illness is so disabling. The presence of preexisting neurocognitive deficits due to serious mental illness complicates the ability to diagnose a neurocognitive disorder, even though people living with serious mental illness face an increase in the risk of developing dementia. Multiple studies of those with schizophrenia, bipolar disorder, and major depressive disorder show significant increased risk of developing dementia compared to the general population [2, 4]. Many primary care providers have difficulty differentiating NPS caused by dementia from the NPS caused by other psychiatric illnesses. Given that serious mental illness and dementia involve both a person's daily functioning and their neurological systems, it is not surprising that many of the same symptoms are found in those living with all these illnesses [1].

Dementia as a Life-Limiting Illness

A major component of person-centered care for those who have a life-limiting disease is maximizing functioning and maintaining or improving quality of life when possible. Palliative care is often confused with hospice. Palliation and the provision of palliative care emphasizing aggressive management of symptoms that cause or increase suffering are indicated whenever a life-limiting disease is diagnosed. When it is no longer possible to maintain or improve the quality of life due to the life-limiting nature of these progressive illnesses, it is the standard of care to consider a shift of the goal of care to comfort and relief of suffering. Medical professionals, as well as the public at large, have been reluctant to acknowledge the relentless and progressive nature of dementia. Some of these illnesses progress over as many as 20 years and therefore it is less obvious that they can be a cause of death. This attitude and the accompanying reluctance to diagnose people with dementia have been slowly changing. It is important to recognize that these illnesses are progressive until life ends. People who are dying, and their families, deserve the chance to process their grief and emotions related to dying. This is one way to decrease suffering. Too often family members only realize that someone living with dementia is near death when they are in their last weeks. As with all serious illness, it is advisable to complete advanced care planning and regularly reassess the goals of treatment and care. This allows for the provision of palliative care to minimize suffering whenever possible. This is reviewed more thoroughly in a later chapter.

Behavior Is Communication

All behavior is communication. This applies both to those who have dementia as well as all humans. Most communication, in fact, is nonverbal. Body language and tone of voice combined are thought to outweigh the content of words. Despite this fact, the human brain appears to be quite focused on verbal information. In clinical practice the tendency is to believe what people say with words even when their ability to use language is impaired and/or their actions repeatedly demonstrate something different. When working with those with dementia, this may be part of the laudatory desire to respect people as adults. Those with major neurocognitive disorder as well as other brain illnesses are often unable to use language with the level of specificity and accuracy that was used prior to the development of dementia. Further, due to memory and/or executive functioning deficits, people may mean what they say but be unable to carry through with actions. One of the advantages of language is that words enable rapid and succinct communication. However, because almost all forms of major neurocognitive disorder impair the ability of the brain to use and understand language, it is essential to include the metamessage that a person's behavior is communicating in addition to their words when planning and using communication. Note that the timing of the impairment of the verbal centers in the brain is different for different neurodegenerative illnesses. This is one of the many reasons why it is essential not to consider dementia or major neurocognitive disorder as a single entity. Because of these challenges with limiting communication merely to language, the authors of this text advocate analyzing what people are trying to communicate by combining information from verbal language, tone of voice, body language, and actions to best understand what people with MNCD want to communicate and plan for addressing this communication.

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Chapter 2

The Team Approach for Those with MNCD: Interdisciplinary and Collaborative

Maureen C. Nash

A high-functioning team is critical when caring for older adults with dementia. Theoretically a simple concept, teams become complicated when working with those having multiple and complex functional needs. Healthcare and the provision of daily services for older adults with competing opportunities and challenges are difficult at times. Definitions, benefits, and drawbacks of multidisciplinary and interdisciplinary teams focusing on collaboration will be explored in this chapter. Potential members of a team, their scope of practice and roles on a team specifically designed to work with those with major neurocognitive disorders, and examples of potential roles will then be reviewed. There are multiple visions for what constitutes an ideal team. The actual team that one is a member of is often driven by external constraints unrelated to the ideal model of care, for example, the existence and experience of specific professionals in the area one lives, the financial resources of the person, and the specific healthcare or social system one belongs to in addition to other indi-

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vidual factors. Similarly, the type of team one is likely to need depends on where one is living: one's own home, an assisted living facility, a memory care community, or a nursing facility. Communication is the cornerstone of successful teamwork as well as high-quality care. Several techniques to enhance communication in teams will be discussed.

There are many examples of the need for good team-based care of those living with dementia. Studies of older adults newly receiving community-based long-term supports and services (LTSS), many of whom have dementia, found common barriers to person-centered care: disorganized and poor staff communication; substantial delays in receiving care when older adults were transferred to the emergency department; perceived inaccessibility and poor responsiveness of healthcare staff in hospital settings; little to no transfer of information about individualized needs, goals, and plan of care at the time of transfer; limited preparation and time for staff in both LTSS and hospital settings to respond to residents' acute and long-term needs; and lack of mutual respect between acute and long-term care staff [12]. These are the types of challenges that a successful team implementing comprehensive person-directed and person-centered care can minimize.

Individual Providers Versus a Multidisciplinary Team Versus an Interdisciplinary Team

Usual Care

When there are a group of individual providers, different specialists and professionals may not even know that others are seeing the person. Even if they are aware that others are involved, they do not share records or assessments; they do not have team meetings to discuss a person and their situation. The healthcare providers do not think of themselves as part of the same team with each other, the person living with dementia, and the person's family or other natural supports.

Example of several independent providers when someone is living in their own home:

- Jane is seeing a cardiologist for heart problems, her primary care provider (PCP) for other chronic conditions, a home health speech therapist (ST) for swallowing problems, and a private care aide for activities of daily living (ADL) assistance. Each provider assesses from their discipline's perspective the developments and implements a plan for Jane. The benefit here is that Jane is accessing multiple kinds of needed care: medical including cardiac, ST, and ADL help.

How this can become a challenge:

- It is entirely possible that none of these individuals are aware of the other's involvement in the care of the person living with dementia. Unless the professionals specifically ask Jane or her family, it may not occur to Jane to mention the other professionals. Even if asked, Jane may not recall who she sees for what due to her dementia. Potential problems include Jane cannot swallow all of her pills but the cardiologist assumes that she is taking all of her medications as prescribed. This leads her to increase doses based on this misunderstanding; the care aide is putting some of Jane's pills in orange juice without realizing that some pills are inactivated due to the acid in orange juice. Then there is an acute crisis caused by not receiving enough cardiac medication. Jane is hospitalized, and most of her medications are restarted as prescribed though the doses of some are increased further resulting in a significant inadvertent overdose. Those healthcare providers in the hospital cannot easily figure out what is happening in a way that is quickly helpful to Jane. She ends up with a much longer hospital stay leading to muscle loss and functional decline. Her ability to ambulate deteriorates, and she is not safe to return home.

How this challenge could have been different:

- Jane's daughter accompanies her mother to most of her medical appointments. When she is unable to do so, she calls the healthcare professional's office prior to the visit and gives an update to the medical assistant in the office with details about the medications her mother is taking or not taking and a list of all other healthcare providers and their contact information currently involved in her mother's care. She makes sure to get a report from the ST as well as the cardiologist, PCP, and other people involved in her mother's care, and she personally makes sure that information is provided where needed. Jane's daughter is acting as Jane's care manager in this role. It takes time, effort, and financial resources for Jane's daughter to make sure her mother's needs are met. This may not help with Jane's swallowing problems but the excessive medications in the hospital could be prevented.

Multidisciplinary Care

Multidisciplinary teams consist of several individual clinicians from different disciplines who independently evaluate and develop a plan of care for a person's problems that fall into their own area. These care plans are implemented parallel to one another, and there is no specific consideration of their mutual interactions. The assessments and plans are provided to all team members, and there are team meetings, though not every team member will attend them. One advantage of this model is access to multiple different clinical points of view. Team members theoretically can use informal relationships to improve the general knowledge of other team members. One challenge of this structure is that there is often no unifying philosophical framework. Some of the team members will likely feel pressure to adapt their own clinical lens to the culture of the dominant discipline. An example of disciplines with varied philosophies includes the differing cultures of nursing, social work, medicine, and rehabilitation. Each discipline has its own tradition, language, and terminology that may clash with another's. Often the PCP is thought

Example of a multidisciplinary team when someone is living in an assisted living facility (ALF):

- John has been told he has a mild form of dementia. He has a PCP for acute and chronic health conditions who wrote the admission orders for him to move to the ALF. There are aides at the ALF who provide him with ADL help, there are medication aides who administer all of his prescribed medications to him, there is an activity director at the ALF who did an assessment and provides activities for all of the resident's to attend, meals are provided by the ALF, and there is an RN at the ALF who can assist with medication questions and communication with his PCP. John has a service plan at the ALF, and he and his daughter have attended meetings together with the ALF staff to discuss his care needs and how he is doing.
- As is common with most of those with dementia, John is having sleep problems. He tells his daughter about this, and she buys him an over-the-counter sleep aide without realizing that it is anticholinergic and worsens confusion in most older adults, especially those with dementia. Because it is an over-the-counter medication (OTC), it does not occur to her to tell the ALF or his PCP.

How this can become a challenge:

- John becomes more acutely confused and accuses his neighbor of stealing from him leading them to have a physical altercation. The RN who is present at the assisted living 2 days per week comes in for her regular shift and is told that John is having aggressive behaviors. She is unaware of the new OTC medication. She goes to talk to John and finds that he is extremely anxious. She calls his PCP and asks for medication for anxiety. The PCP writes a prescription for an antianxiety medication that leaves John more confused and at higher risk of falling. He does fall and is hospitalized for evaluation. The assisted living tells his family that John is no longer a good fit for their facility and requests that they find a different setting for him to live in.

How this challenge could have been different:

- As soon as the RN at the ALF realizes that John is acting very differently, she asks him what has changed. John states only that the neighbor is now stealing from him. The RN also calls his daughter to ask her if she knows of anything being different for John. She is told about the new sleep medication. She lets John and his daughter know some of the problems with these medicines. She asks John's daughter to come and remove this medication from John's room. The RN makes an appointment for John to see his PCP about his sleep problems as well as what happened with the OTC pill including the delusion about theft. The PCP does a full assessment of John and his medications. He orders functional cognition testing and a home safety evaluation from occupational therapy (OT) to make sure John has what he needs to succeed at the ALF.

of as the team's medical leader though the PCP is unlikely to attend a routine team meeting.

When a multidisciplinary team is used in the care of someone with dementia, it is especially important that family members or other natural supports are included as members of the team and educated about sharing concerns they have or learn about. It is important that they know that the ALF and PCP need to know about all medications even those from the corner drug store. Even if not all members of the team are in the same meeting (such as the PCP), there is coordination of information among everyone on the team.

Decision-making can become “siloed” where one discipline does not seek nor value input from other team members. For example, if the PCP in the example above did not listen to the concerns of the ALF nurse and did not consider all the factors that were involved in John’s recent reaction, he may not have ordered the OT assessment to maximize John’s ability to stabilize at the ALF. A common example is when there are multiple medical specialists involved in caring for the same person, but they prescribe medications that counteract each other. The older adult with dementia may suffer and families may be confused. End-of-life issues are a particularly vulnerable area where siloed care can be a source of long-lasting distress and self-doubt for the person with dementia and their families. The chapter on palliative care has information about advanced care planning and other factors to consider that may decrease distress when one’s dementia advances. In addition to communication challenges and the risk of competing priorities and medical interventions, interpersonal conflict occurs more commonly in multidisciplinary team. This is especially so when there is uncertainty about the expected role of each team member and the existence of different value systems [6].

Interdisciplinary Teams

A more collaborative and interactive model than multidisciplinary teams are interdisciplinary (also known as interprofessional) teams. The hallmark of the interdisciplinary team approach is a group from varied professional backgrounds collaborating with unified goals and a common purpose. Resources and decision-making are shared as well as the responsibility for outcomes. This approach is a preferred decision-making and care planning model when working with older adults with complex medical and social needs. There is greater potential for creative problem-solving when those with varied training and experiences can work on meeting the care challenges that naturally occur in those with dementia. A high-functioning interdisciplinary team will have a process for professionals to develop an integrated and cohesive plan to assess and address the needs of those with dementia [13]. The strength of the interdisciplinary team is based on the depth and creativity of discussion and the ability to be flexible and adjust to the changes that the person with dementia will experience. This model involves an interdisciplinary team providing multicomponent interventions with a shared understanding. The goal is delivery of person-centered care to those living with dementia and their caregivers using comprehensive assessment tools to measure signs and symptoms, meet needs, and monitor interventions and the individual's response. Care protocols need to be driven by person-directed goals and a shared decision-making process with measurable outcomes and quality indicators. The interdisciplinary team can provide the most comprehensive care. Note that collaborative care is defined differently among differing healthcare disciplines. Current evidence supports improved outcomes with the collaborative care model in primary care. Collaborative primary care usually involves teams of physicians, nurse practitioners, nurses, and social workers. Case management and care coordination are key factors. When collaborative care focusses on working with those with dementia, disciplines that have been involved include occupational therapy, geriatricians, pharmacists, physical therapists, psychologists, geriatric psychiatrists, applied behavioral analysts, personal care aides, nurses, and dieticians, among others. Each member of the care team provides their own vision of the situation, providing explanation and problem-solving to enable the person and their caregiver's broad support, comprehensive assessment, and care planning. It is important to remember the importance of including and consulting other members of the team that are often forgotten, including the person with dementia, their family/natural supports, housekeeping, direct care workers, and dietary staff, when present. These sometimes-overlooked team members often have unique and intimate information that is extremely helpful in planning and implementing care approaches. The idea is to combine the strengths, knowledge, and insights of all team members while minimizing the chance of missed opportunities to improve care and communication [5].

Shared decision-making (SDM) is essential for truly person-directed and person-centered care: Essentially the person's priorities, abilities, character, and interests should inform all decision-making. SDM implies that the healthcare provider is acting as a consultant to the decision-maker – the patient. Many times, professionals and caregivers assume that a person with dementia is incapable of participating in and making decisions. SDM is different from substituted decision-making if the person's current wishes are not consulted [3].

Three ways those living with dementia conceptualized SDM were:

- Subtle support versus taking over
- Hanging on versus letting go
- Being central versus being marginalized or excluded

For many people with dementia, the participation or "sharing" in the decision-making process is as (if not more) important than making the decision itself [3].

Interdisciplinary team care involves a partnership between all involved health providers and the person and their family or natural supports participating collaboratively. Shared decision-making regarding both health and social issues is essential to full team partnership. Interdisciplinary collaborative practice depends on synergistic communication and decision-making. Each profession shares their own knowledge and skills. Ideal elements of collaborative practice include shared responsibility, accountability to each other, coordination of efforts, regular communication, cooperation with each other, assertiveness in expressing thoughts and ideas, shared autonomy, and, finally, mutual trust and respect. It is this partnership of an interdisciplinary team working toward common goals that leads to improvement in clinical and functional outcomes for the person living with dementia. Collaborative interactions exhibit a blending of professional cultures and are achieved through sharing skills and knowledge. Success depends upon all team members recognizing each of their roles as important to the team. Further, open expressive and receptive communication, the existence of autonomy for each team member, and equitable access to resources are key. Poor interdisciplinary collaboration can have a negative impact on the quality of care. Thus, skills in working as an interdisciplinary team are quite important for high-quality care [2]. Interdisciplinary team care implies that everyone has some ownership for each part of the care and the whole team is responsible for all tasks and assessments. This distribution of responsibility is a major risk point in interdisciplinary care. When something is everyone's responsibility, it can become equivalent to being no one's responsibility. This is one reason coordination, comprehensive communication, and having a specific person assigned to verify every task's completion are vital to team success [14].

Collaborative Interdisciplinary Teams

Interdisciplinary teams are studied in several diverse types of settings. One effort is the Marian S. Ware Alzheimer Program at the University of Pennsylvania. This philanthropic and university partnership was designed to advance knowledge in four areas. They sought to improve the integration and continuity of Alzheimer's disease care, identify biomarkers for early diagnosis of Alzheimer's disease and related neurodegenerative cognitive disorders, use clinical trials to more effectively test new Alzheimer's disease interventions and translate them into real-world clinical practice, as well as discover disease-modifying treatments for Alzheimer's. The Ware Program focused first on using an interdisciplinary team to address acute illness episodes in those with dementia. These types of hospitalizations are frequent, disruptive, costly, and often associated with poor outcomes. Specific areas of concern are accelerated cognitive, physical, and functional decline that occurs in those with dementia and the high rates of adverse events and rehospitalization. The Ware Program used an interdisciplinary team of scholars from nursing, medicine, healthcare economics, and biostatistics to design interventions to better address the complex care needs of this high-risk group of individuals and their family caregivers. They also focus on increasing the efficiency of the healthcare system. The program uses their findings to influence healthcare policy and improve clinical practice. This led to the development of the transitional care model (TCM) for those with dementia and their caregivers. The TCM uses a person-centered approach by focusing on identifying older adults' health goals, coordinating care before, during, and after every episode of acute illness. The TCM model evolved from a multidisciplinary model to an interdisciplinary model involving physicians, nurses, other healthcare staff, as well as the person and their caregivers working together. A major component of this model is the development of a specific, clear care plan and involvement of the person and their caregivers on the planning, details, and implementation of care. They were able to show fewer hospitalizations as well as fewer rehospitalizations. These results are cost-effective, but more importantly these types of outcomes decrease stress for those living with dementia and their caregivers, decrease risk of more rapid decompensation, as well as minimize those with dementia having to endure painful medical procedures that do not offer them a benefit in quality or quantity of life [12].

One particularly robust example of the interdisciplinary team model is the Program of All-inclusive Care for the Elderly (PACE). There are now 124 PACE programs operating 255 PACE adult day health centers in 31 states [10].

PACE programs serve frail older adults, known as program participants, who meet state Medicaid criteria for nursing home level of care through a specific Medicare PACE program. To enroll in a PACE program, one must live in the service area of the PACE program and be able to be cared for safely in the community (not a nursing facility) with the supports of the PACE program at the time of enrollment. Most PACE enrollees are dually eligible for Medicare and Medicaid and many have a dementia diagnosis. PACE uses an interdisciplinary approach to care with a specifically large interdisciplinary team (known as the IDT). The IDT consists of a medical provider (including nurse practitioners in some states as well as physicians), adult day health center and home care nurses, personal care aides, master's level social workers, occupational therapists, physical therapists, activity coordinator or recreational therapist, dietician, drivers, home care coordinator, and day health center manager. The IDT operates collectively in a care management role. IDT members jointly and regularly assess and reassess participant needs. Based on these assessments, care plans are developed and regularly updated. The model honors an individual's wishes to live in the community as much as possible. Being much more risk tolerant than most traditional healthcare is essential for a PACE IDT. Another way to view risk tolerance is seeing choices as participant centered, allowing frail older adults to make choices that might have greater risk but are aligned with a person's values and wishes. The interdisciplinary team develops a unified care plan. This care plan is the central organizing document describing all care provided to the participant. When indicated, other services such as PACE employees, or other contracted providers provide speech therapy and behavioral health services. This ensures that all medically indicated services are delivered in a person-directed way. Additionally, the IDTs monitor participant status and care, adjust services, track quality and costs. Considerable staff time is devoted by team members to formal and informal idea and information exchange. The structure and process of team care in this model are firmly grounded in what has been referred to as a "geriatric interdisciplinary team." This type of team care has been found to be particularly effective when working with older adults who have significant multiple disease states. Group decision-making and consensus building, inherent in such teams, facilitate better care management and service performance. An emphasis on providing significant care to maintain function is one key component of this chronic care model rather than focusing on acute medical events. Ongoing rehabilitation and other services are not limited to those who continue to improve. Another key to successfully meeting frail older adults' needs is identifying when it is appropriate to shift the goals as the end-of-life nears. Evaluations have shown that PACE program participants experience a higher quality of life and greater confidence in their ability to maintain control of their lives and deal with day-to-day problems, in part through spending fewer days in hospitals and nursing homes [8].

The Indianapolis Discovery Network for Dementia has developed a team-based pathway through the Healthy Aging Brain Center in Indiana. This team developed a care pathway starting with an initial cognitive assessment which includes neuropsychological testing, brain imaging, medication review, and structured neurological and physical evaluations. An important part of the team is the person with the neurocognitive disorder. The person living with dementia and their family provide context, life philosophy, and personal details which inform all aspects of the treatment plan. The personal treatment plan that is developed includes recognizing potentially harmful medications, prescribing new medications where indicated, initiating brain and physical exercise regimens, training in problem-solving, and working on reducing stress to improve daily life. Physicians, nurses, social workers, occupational therapists, and other staff members work closely with both the older adult and family caregivers. Both the evaluation and the plan include information obtained from the exam room and the home. Communication occurs face to face, as well as over the phone and via email. The goal for both brain and physical health is to deliver care to improve and restore function where possible, maintain function when able, and support as functioning declines. Even as functional abilities of the person decline, resilience and support can be built into the environment around the person and their family through the collaborative efforts of the person, their family, and the interdisciplinary team members. The Healthy Aging Brain Center care model also provides additional resources to the primary care physician for more effective and efficient management of the patient's dementia and/or depression, reduces emergency department visits and hospitalizations, and encourages the use of medications that are not harmful to older brains [1, 4].

Responsibilities and Relationships Among Different Team Members of an Interdisciplinary Team

The art of a successful team when caring for someone with dementia is collaboratively combining expertise, talent, and perspective of all team members to assist and support the central member of the team, the person living with dementia. The various healthcare members assess the person functionally, medically, and socially. Treatment and intervention options are described to the person and their caregivers so that choices can be made which are consistent with the person's cultural values and personal beliefs using an SDM model. Discussion of potential roles for various team members working with someone living with dementia will be reviewed. Figures 2.1 and 2.2 are examples of common interdisciplinary care teams for those living with dementia.

Members of an IDT

The Central Member of the Team Is the Person Living with Dementia Themselves For an empowering care plan, one needs comprehensive information on the social history of the

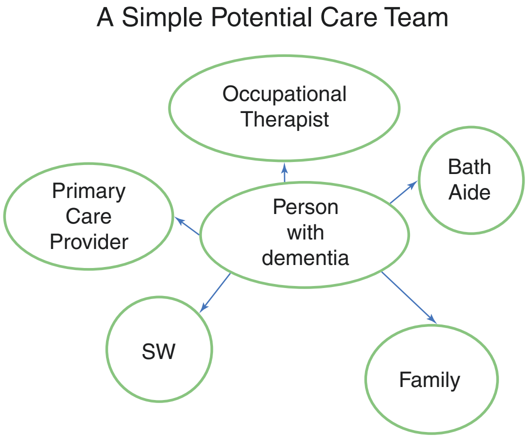

FIGURE 2.1 Example of a common interdisciplinary care team when someone is living in their own home or with family (Copyright Maureen C. Nash, MD. 2018)

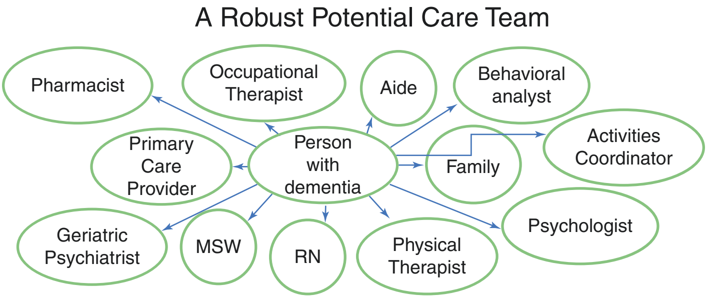

FIGURE 2.2 Example of a common interdisciplinary care team when someone is living in a facility experiencing more significant NPS (Copyright Maureen C. Nash, MD. 2018)

person, career details, support networks and involved family members, information sharing agreements, details of all medical conditions, and medications. One needs to know what the person understands about their dementia and what they expect to occur in the near and midterm future. Any specific goals and actions for how the person plans to manage his/her health and well-being and the support available to them should be identified. Periodic updates to the support team need to be made as family, friends, and professional staff enter and leave a person's life. If the person was diagnosed early in the course of the disease, then they will be able to more fully participate in providing information. Some people may wish for a referral to a research center specializing in dementia care, hoping to improve the knowledge available for future generations. When a diagnosis is first made, it is timely to help a person identify personal, unfinished business and think through what actions make sense. If the diagnosis occurs later in the disease process, family, friends, and other natural supports may need to fill in details. Regardless of the stage of the disease, it is always recommended for people with a life-limiting condition that there should be conversations about the person's goals of care and advanced care planning. When someone lives to the late stages of dementia, the person may lose the verbal and cognitive skills required to express their wishes. In that case, identifying past wishes and philosophy are important. It is also vital to continue to listen to the communication of a person's wishes by observing and analyzing behaviors. As stated in the first chapter, all behavior has meaning. For example, the person may refuse therapy, even when approached in a skillful manner, or may begin to refuse to eat. This is where a good, collaborative team can shine, sorting out what the person is telling them with their behaviors. Appointing a healthcare power of attorney and recommending consideration of a financial power of attorney should be reviewed. It is important for the person with dementia to document who they want to make decisions for them if they cannot make them for themselves. It is also essential to encourage healthcare powers of attorney and next of kin to have open and honest discussions around future end-of-life choices.

Each professional member of the team first considers what their discipline contributes to the assessment and care recommendations. Which of the person's goals are being addressed and what is the evidence that the suggested interventions will help move toward the goals the person has outlined? Clearly delineate the treatment objectives specific to this person, currently, for all recommendations as well as what evidence supports the recommendations. Consider whether there are missing team members and consider need for other consultants depending on the specific situation. Review what other information is needed from the person or their family to guide ongoing care. Whenever there is a transition from one care setting to another, for example, moving from an independent home to an assisted living facility, or a transition from one healthcare professional to another, such as changing primary care providers, there are many risks of loss of information and disrupted continuity of care. Also, whenever a person has a change in condition, either their health takes a significant turn for the better or for the worse, assessments need to be repeated and goals readdressed. Risks around transitions are multiplied when the person has neurocognitive deficits because their ability to communicate their history may be compromised. The person may not be able to convey their goals or desires clearly compared to other times in their life.

Primary Care Provider (PCP) May Describe a Physician, Nurse Practitioner, and/or Physician Assistant Their role centers on being the first point of contact for the assessment of acute symptoms and following those with chronic conditions providing ongoing continuity of care. There is also a component of care coordination whenever specialist care is needed. This becomes especially important when working with older adults having multiple medical comorbidities where the US has many healthcare guidelines. This information is one vital part of the care plan. Changes in condition, unusual or atypical presentations, are often assessed first by the medical members of the team. Tests including imaging, lab work, and other medical procedures are considered and ordered when indicated and consistent with the person's goals of care after shared decision-making discussions. Referrals to other consultants are coordinated as needed. Information after evaluation and testing is communicated to members of the team and incorporated into the care plan.

Occupational Therapist (OT) Uses Objective Evaluations to Determine Individual Strengths, Impairments, and Performance Areas Requiring Intervention OTs are experts at evaluating creative ways to compensate for deficits and then can adapt the environment or use strategies so that a person's strengths can best serve their goals. Specifically, OTs focus on four areas: health promotion and maintaining strengths, remediation interventions to improve the performance of activities of daily living and functional mobility, assist with maintaining habits and routines to prolong independence, and modifying the environment to be as supportive and safe as possible. OTs use critical and creative thinking to ensure the environment is best suited to enhance functioning. Information after assessment is communicated to members of the team and incorporated into the care plan.

Registered Nurses (RN) Most Often Serve as Care Managers When Working on a Transdisciplinary Team Working with Someone with Dementia They help to plan, coordinate, and implement the overall approach to care. Other specific tasks may include nursing assessments, memory testing, skin and wound checks, explaining instructions and follow-ups, medication reconciliation, coordinating care aides, and assisting with information exchange between healthcare professionals, as well as with the person with dementia and their family. Education about medical problems and tasks such as wound care and foot care often fall under the purview of RNs. Information after assessment is communicated to members of the team and incorporated into the care plan.

Social Workers (SW) Are Experts at Gathering and Integrating Biopsychosocial Information into the Care Plan The initial social work assessment is a comprehensive biopsychosocial history including significant life events (family of origin, relationships and family, employment, lifestyle preferences and values, spirituality) that the person has experienced throughout his/her life. This initial assessment will note behavioral health issues including any history of trauma. The social worker explores what is important to the participant as they approach this phase of their life with dementia. Cultural, racial, gender, social, and other value beliefs and preferences are essential components of a person-centered care plan. The social worker contributes perspective and knowledge about the individuals and current emotional stability, quality of life factors, living environment and how it supports the person with MNCD, family system, and coping. The social work perspective is generally a strength-based assessment that parallels the person-centered care planning. The social work contribution to the care plan is a collaborative process including contact with the participant's family and caregiver for collateral information and assessment of the family and caregiver needs.

Housekeepers Work to Organize and Clean in a Person-Centered Way This is an example of a nearly invisible member of an interdisciplinary team in a facility setting. A housekeeper may be the first person to notice when someone is no longer engaging with their environment. This person will see that nothing has been moved or that the person used to engage in brief social interactions but is no longer doing so. A housekeeper can help implement a care plan by engaging someone in meaningful conversation about books or other belongings. This staff member can ask the person living with dementia for their opinion, letting them be the expert for example. A housekeeper is likely to see someone multiple times per week, giving them keen insights into a person's habits and routines and able to let other team members know when something has changed.

A geriatrician or physician specializing in care of older adults or gerontologist, an MS or PhD in gerontology or related field, can be a valuable consultant if one is not on the primary team caring for the person. This type of consultant can be especially valuable at the beginning of developing a care plan or at major times of transition. These specialists have the background to describe familiar challenges and point out areas commonly challenging for older adults. Care of elders is a specialty that requires a deeper yet broader knowledge of who the person is and was and realistic goals for the future. Lacking the focus in deciding on a plan of care can lead to siloed, inappropriate, costly, and painful interventions.

Pharmacists Are Experts in Medications and Drug Interactions They have the background to review and help coordinate prescription and over-the-counter medications as well as assess a person's ability to safely self-administer medications. Review of the medication list can reveal medications that may be worsening cognition, behaviors, and other medical symptoms. The pharmacist can give tips on when to take or avoid certain medications, review for drug-drug interactions or drug-disease interactions, and bring questions and issues to the attention to the person and other care team members.

Psychiatrists and Psychiatric Mental Health Nurse Practitioners Who Have Experience in Geriatric Care Are Experts in Assessment of Neuropsychiatric Symptoms in Those with Mental Illness as well as Dementia These professionals often have a long history of working collaboratively in team environments. They are experts in knowing when to use or avoid medications especially for neuropsychiatric symptoms. Psychiatrist's training overlaps the training of neurologists. They have significant education and experience in working with both neurologic and psychiatric illness. They have experience and expertise at discerning delirium from dementia and are often knowledgeable on drug-drug and drug-disease interactions in this population. Most geriatric psychiatrists and neuropsychiatrists have extensive experience in working with those with dementia.

There are many other potential members of an interdisciplinary team. The exact composition of a team will depend on the past, current, and expected future challenges that a person has as well as where they are living and with whom. It is quite important to periodically reassess the team members, matching the current needs of the person living with dementia to the available resources.

Measuring Outcomes of Interdisciplinary Collaboration Around Older Adults

The overall effects of interdisciplinary interventions for older adults are generally positive, but assessment of interdisciplinary care is based on heterogeneous outcomes. Most of the evidence has come from nursing homes, hospitals, and primary care homes as well as specialized programs such as PACE programs. There is evidence that interdisciplinary care can lower overall healthcare costs. Other outcome indicators of interdisciplinary care for older adults showing the most positive effects include measures of collaboration and at the level of the person's experience. Outcome indicators which are key elements of collaboration include improvements in professional and personal satisfaction as well as the quality of care. On the individual person's level, outcome indicators with the most evidence include decreased pain, decreased fall incidence, improved quality of life, maintenance of independence for daily life activities, decreased depression and agitated behavior, decreased transitions of care, decreased length of stay in hospital, decreased mortality, and decreased period of rehabilitation [13]. PACE programs with their extensive interdisciplinary teams have demonstrated decreased cost of care while improving quality of life as evidenced by increasing the amount of time living in a community setting. Surveys indicate that comparison of other home- and community-based services enrollees with PACE enrollees showed that PACE participants had better health management outcomes including having advanced care planning documents such as advanced directives and healthcare powers of attorney in place, reported less pain that interfered with normal daily functioning, and reported fewer unmet needs in getting around and dressing [9].

Communication: Central to all Teamwork

All well-functioning teams communicate regularly and clearly. Structured communication enables consistent, succinct, and respectful sharing of information. This allows for a shared understanding of the current situation and plan as well as enabling the incorporation of added information and regular updating of the care plan. The foundation of collaborative interdisciplinary teams includes trust, respect, shared accountability, and shared decision-making. All of these require effective communication among team members.

Huddles are a common check-in communication tactic. They are short, daily sessions for the care team to rapidly prepare for managing the day. As an excellent form of communication, it is most often used in a facility setting or a provider's office but could be adapted for use in a person's home when there are different team members handing off duties to each other. Huddles are often quite brief such as 5 minutes at the start of a day. Topics may include anything from adjustments to workflow or schedule, crisis management, and special challenges that are expected to arise. In a clinic setting, these will often be documented, perhaps in the electronic health record. Others use a white board to note agenda items throughout the day for the next day's discussion. Patient-centered medical homes are required to document huddles. In an ALF, Memory Care Unit (MCU), or NH, huddles can be used to quickly relay community-wide events or planned disruptions, as well as passing on brief updates about community members.

Team meetings are more formal meetings to review current information, regular reassessments of the person's situation, and care plan and/or to make decisions. Training might be included in this category of communication. When the person living with dementia is attending, special efforts are needed to make sure that the pace and content of the conversation is appropriate to the person's needs. Remember that SDM research has shown how much people living with dementia value being a participant in the discussion rather than being talked about or talked over.

Family conferences are a common and foundational forum for communication. Healthcare professionals, including the

Outline for an Initial Care Conference After Assessments

- Introduction of everyone and their role.
- Review purpose of meeting and the time frame available.
- Presenting problem, if any, that started assessment process.
- Outline of tests and assessments performed with explanations of results in lay language.
- Diagnoses.
- Stop and address any questions up to this point.
- Discuss trajectory of disease and where person is at this time.
- Review expected timelines for future when known.
- Discuss potential behavioral and pharmacological interventions.
- Answer questions.
- Explore fears, hopes, and aspirations for the future.
- Review and agree on next steps.

care coordinator, community representatives, the person and/or their family, and other natural supports meet to discuss options for treatment, to help the patient and family prepare for a significant change in lifestyle or to face a life-changing event. Careful preparation is needed to ensure a successful conference. Important tools that are complementary to such conferences are shared decision-making and patient self-management tools [11]. It is also important to remember that the definition of family or other natural supports will vary from one individual to another.

There are many different tools available to improve and structure communication. It is important that the interdisciplinary team has several different standard types of communication habits. Regular team meetings where a set agenda and process for discussion helps keep communication clear. Tools around contingency planning and ways for team members to discuss acute or unexpected changes are important. Also, communication tools for those who are off-site as well as those within a single facility need to be explored and agreed upon ahead of time. Additionally, ways to communicate during an emergency are important for everyone to know. This enables communication to be appropriate to the situation, happening at the right time, in the right way to meet the needs of the person living with dementia and all those involved in their care [7].

This chapter reviewed some of the advantages of a highly functioning interdisciplinary team approach for those living with dementia. There is good evidence that an interdisciplinary team allows access to high-quality care, an improved quality of life, and improved satisfaction with healthcare. Those living with dementia benefit from a specialized shared decision-making approach. The center of every team is the person living with dementia. The composition of a team will always depend on the specific person and their situation. Finally, the importance of communication is emphasized.

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Chapter 3
Neurocognitive Disorders and Neuropsychiatric Symptoms

Susan S. Rose

Introduction to Neurocognitive Disorders and Neuropsychiatric Symptoms

The brain is a dynamic process undergoing constant development and reconstruction across the lifespan [7], which can be imagined as a process of pruning, maintenance, and regrowth [30]. However, this dynamic process can be disrupted when an individual develops a neurocognitive disorder, such as dementia, a disruption that is characterized by neuropsychiatric symptoms and eventually leads to death.

Prior to the publication of the 2013 edition of the diagnostic and statistical manual of mental disorders (DSM-5), neurocognitive deficits were referred to by the umbrella term of dementia. This led to confusion on the part of consumers, particularly when terms like Alzheimer's and dementia were used interchangeably. The DSM-5, however, refers to dementia in terms of a more inclusive title: neurocognitive disorders (NCD). There are other disorders where cognitive impairment and functional decline occur outside of the degenerative brain disorders known as dementia. As with other versions of the DSM, the latest version encourages differen-

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tiation of *with or without behavior disturbance* [2], but little emphasis is given to the subject of behavior disturbance itself.

This guide strives to rectify the deficit. The use of the phrase *behavioral disturbance* is inherently incomplete. Behaviors are ubiquitous and normal and serve as a principal mode of communication. Behaviors can become the only mode of communication for those who have trouble understanding or using the language. This guide focuses on the prevention and management of neuropsychiatric symptoms (NPS). NPS routinely causes suffering for those individuals with MNCD, as well those who care for and about them. The trajectory of MNCD leads to eventual fatality. Currently, there are no disease-modifying treatments for MNCD. Instead, NPS are quite often the major focus of treatment: Arguably, NPS may be the only current treatment targets for intervention.

The focus on neuropsychiatric symptoms (NPS) is pragmatic as well as compassionate. NPS comprise the leading cause of quality of life concerns for families of individuals with MNCD. It is the NPS, rather than the NCD itself, that leads to placement of individuals in facilities. The authors of this text posit that these abnormal symptoms cause so much suffering that they need to be the major focus of assessment and treatment. Therefore, this chapter will describe types of MNCD in the context of the various NPS that are associated with each NCD. In fact, our focus on NPS is the predominant theme for this chapter.

Neuropsychiatric Symptoms

The term “neuropsychiatric symptom” has historically been used to describe core features of Alzheimer’s disease and related dementias [17, p. 532]; however, a formal operational definition of NPS has not been universally embraced. Many studies recognize the contribution of the Neuropsychiatric Inventory (NPI) [8, 9] and define NPS in terms of NPI items [16, 32]. A 2010 Alzheimer’s Association Research

Roundtable underscored the difficulty identifying and classifying NPS across system clusters, as well as differentiating clear syndromes [17].

For the purposes of this guide, NPS are defined inclusively and comprise those symptoms described in the NPI, including apathy, agitation, anxiety, irritability, dysphoria, aberrant motor behavior, disinhibition, delusions, hallucinations, and euphoria [8]. Additional NPS that cause distress for individuals with NCD and their caregivers include verbal abuse, physical aggression, sexually challenging behaviors, exit-seeking behaviors, vocal repetitions, and screaming behaviors and are therefore included in the inclusive definition of NPS.

Assessment of Neuropsychiatric Symptoms

There are a number of different scales to measure NPS, including the Neuropsychiatric Inventory [8], Behavioral Pathology in Alzheimer's Disease Rating Scale (BEHAVE-AD) [26], Alzheimer's Disease Assessment Scale noncognitive section (ADAS-noncog) [29], Cohen-Mansfield Agitation Inventory [6], and others. The authors of this textbook recommend the Neuropsychiatric Inventory (NPI), developed by the behavioral neurologist Jeffrey Cummings, MD [8, 9].

The NPI is valid, reliable, sensitive to change, and free to use in clinical settings. It is validated across many different NCDs, which differentiates it from many of the other scales that were modelled on the most common NCD, Alzheimer's disease. The NPI uses a screening strategy to *minimize administration time*, examining and scoring only those behavioral domains with positive responses to screening questions. The NPI measures the frequency and severity of each behavior as well as the level of caregiver distress. Information for the NPI is obtained from a caregiver familiar with the patient's behavior.

The NPI covers 12 domains: hallucinations, delusions, elation/euphoria, agitation/aggression, depression/dysphoria, anxiety, apathy/indifference, disinhibition, irritability/lability, aberrant motor behavior, sleep, and appetite and eating disorders. There are a number of different forms of the NPI, including the NPI-NH tested in nursing homes and the NPI-C clinician rating scale [10].

Definition of Neurocognitive Disorders

NCDs refer to conditions in which cognitive impairment is a salient characteristic. Although other psychiatric disorders, such as schizophrenia, may affect cognition, only disorders in which cognitive impairment is a core feature are included in the DSM-5 categorization of NCDs [2]. Additionally, NCDs only include disorders in which cognitive dysfunction represents a decline from prior level of functioning, thus excluding conditions such as developmental delay, or other syndromes in which cognition may have been impaired since birth or early life.

Although dementia is subsumed under the entity *major neurocognitive disorder*, the term *dementia* itself has been retained in the DSM-5 for continuity, as it is the common term for degenerative disorders that generally affect older adults. The more inclusive term, neurocognitive disorder, is preferred for conditions that include younger individuals, such as impairment secondary to traumatic brain injury [2].

The diagnosis of a MNCD requires evidence of significant cognitive decline from prior level of functioning in one or more cognitive domains, such as attention, executive function, learning and memory, language, perceptual-motor, and social cognition or metacognition. Diagnostic criteria also specify that the slope of the decline must be sufficient to affect basic activities of daily living (ADLs) or independent ADLs. Further, the cognitive deficits cannot occur in the context of a delirium, nor should they be more completely explained by another psychiatric disorder, such as major depressive disorder, bipolar disorder, or schizophrenia [2].

Mild Neurocognitive Disorder

MC is a 64-year-old retired secretary. A few months ago, she noticed that she was having trouble remembering tasks. For example, she would go to the grocery store and forget to buy one or two important items. She went to the post office to mail a letter and became distracted by a friend that she met in line. After buying a book of stamps, she was dismayed to find the unmailed letter in her purse. MC recent called you to ask for a referral to a neurologist. "I am sure that I have Alzheimer's!" she tearfully recounted.

Major and mild NCDs occur on a continuum of cognitive and functional impairment. In prior versions of the DSM, MNCD was referred to as dementia, and mild NCD was referred to as mild cognitive impairment.

Mild NCD is an umbrella term that refers to disorders in which the severity of the impairment does not cross the threshold of function. While individuals with mild NCD may demonstrate evidence of decline in one or more cognitive domains (complex attention, executive function, learning and memory, language, perceptual-motor, or social cognition), the deficits do not interfere with the individual's capacity to live independently or manage instrumental activities of daily living [2].

Structural differences exist between the mild NCD subtypes. Peterson [24] found that individuals with amnestic mild NCD were found to have decreased sizes of the hippocampus and the amygdala, compared to individuals with nonamnestic mild NCD [24].

Differences in neuropsychiatric examination include more impairment in memory functions in individuals with amnestic mild NCD, compared to language impairment in individuals with nonamnestic mild NCD [24], consistent with the prevailing theory of amnestic mild NCD as an AD prodrome and nonamnestic mild NCD as a non-AD prodrome [25, 31]. Table 3.1 compares amnestic and nonamnestic mild NCD and major NCD.

Table 3.1 Amnestic vs nonamnestic mild NCD vs MNCD

Nonamnestic mild NCD	**Amnestic mild NCD**	**Major NCD/ dementia**
Memory may be normal, but impairment exists in other cognitive domains, such as attention or language	Memory is impaired but does not cause problems with function	Impairment in memory plus one or more other cognitive domains
Likely non-AD prodrome	Likely AD prodrome	Deficits cross the threshold of functional impairment
Screen for conversion to amnestic mild NCD	Screen for conversion to Major NCD	Treatment is indicated

Individuals with mild NCD should be followed clinically. Currently, annual screening for memory disorders is part of the Medicare guidelines for primary care [5].

Degenerative Neurocognitive Disorders

Neurocognitive Disorder Due to Alzheimer's Disease

AD is an 82-year-old retired dentist. Over the past several years, he has had several minor car accidents, predominantly fender benders. He comes to you for help "dealing with those idiots from the DMV" after having his driver's license suspended. He mentions that he is no longer talking to his daughter, although they have had a close relationship in the past. He pounds his fists on your desk as he complains that she will no longer allow his grandchildren to ride with him. You notice that AD seems more disheveled and disinhibited than he has in the past.

The most commonly diagnosed neurocognitive disorder in older adults is Alzheimer's disease (AD), accounting for nearly 500,000 new cases of Alzheimer's disease each year [12]. Major or mild NCD due to AD should be suspected when there is evidence of (1) a causative Alzheimer's disease genetic mutation from family history or genetic testing, (2) declining in memory and learning plus one other cognitive domain, (3) steady and progressive decline, without extended plateaus, and (4) no evidence of any other contributory neurodegenerative, cerebrovascular, or other systemic disease or condition to explain the cognitive decline. Probable AD is diagnosed if a family history or genetic mutation is present or if the individual meets all of the remaining criteria; otherwise possible AD should be diagnosed. Mild neurocognitive disorder due to probable or possible AD should be considered for cases that meet the appropriate criteria, but the deficits have not yet begun to affect daily functioning [2].

Neuropsychiatric Symptoms Due to Alzheimer's Disease

NCD due to AD presents with an insidious onset, best described as slow and gradual. Depression and anxiety are increasingly recognized in mild NCD due to AD; in fact, approximately 80 percent of individuals with minor NCD due to AD experience NPS of depression or apathy [2]. Other early symptoms include impaired ability to form new memories; both registration and recall are affected. Language impairment occurs early in the trajectory, and word-finding difficulties are common. Visuospatial impairment also occurs early in the course of the disease; in fact, parking lot accidents and near-misses are common red flags.

As the NCD moves from mild to major, the severity of NPS grows to more commonly include psychotic features, irritability, agitation, combativeness, and wandering. Affect and personality changes may occur in the early stages, but impairment in executive functioning tends to be progressive, as the disease progresses. Paranoia and delusions, most commonly persecutory delusions, are prevalent in mild-moderate

Alzheimer's disease. Sleep disturbances and apathy are frequently found in both mild and MNCD due to AD.

Later stages of MNCD due to AD are commonly associated with motor impairment, gait disturbance, dysphasia, incontinence, myoclonus, and seizures [2]. Agitation, including combativeness, as well as disruptive motor and vocalizations, is common in moderate to severe Alzheimer's. Delusions may occur early in the course of the disease, but hallucinations tend to occur later in the trajectory [11].

Etiology and Treatment of NCD Due to Alzheimer's Disease

Risk factors for Alzheimer's disease include age, family history, and head trauma. Although the aging process does not cause AD per se, age remains the most salient example of correlation without clear etiology of causation.

There are numerous theories for the development of AD, most having to do with cholinergic deficiency. The nucleus basalis of Meynert located in the basal forebrain is the principal site of cholinergic cell bodies thought to mediate memory, learning, and judgment. Deficiency in cholinergic functioning causes disruption in memory. Cholinergic neuronal functioning is one of the earliest neurotransmitter changes in AD. Progressive and downhill, the most damage to the cholinergic system occurs during the first year of symptoms. Unfortunately, by the time the cognitive deficits become apparent, damage has already occurred to the amygdala and hippocampus.

Because Alzheimer's is considered a deficiency of acetylcholine, a trial of cholinesterase inhibitor (ChEI) is considered first-line treatment for MNCD due to AD. The most commonly used ChEIs in the USA include donepezil, galantamine, and rivastigmine. Other ChEIs, such as tacrine, are not currently available.

ChEIs are the most effective for cognition in the early stages of AD. ChEIs require intact postsynaptic cholinergic receptors in order to receive the benefits of enhanced choline; thus they have the most efficacy when postsynaptic cholinergic targets are still present. That said, ChEIs have considerable utility in management of NCD-related NPS, especially as the severity of the NPS increases [22].

Glutamate antagonists, such as memantine, are also useful for AD. These agents inhibit the excitotoxic action of glutamate by blocking noncompetitive N-methyl-D-aspartate (NMDA) receptors and are thought to help restore physiologic function of neurons [14]. They can also play a role in mitigating NPS, such as anxiety. More consistently calming than ChEIs, glutamate antagonists have an appreciable anxiolytic benefit because they block the excitatory properties of glutamate.

Depression and anxiety are commonly seen in individuals with NCDs. Unlike a primary depression, dementia-related depression and anxiety are treated differently than primary anxiety and depressive disorders that developed prior to the onset of dementia. While antidepressants may be the staple for primary anxiety and depressive disorders, they tend to be much less helpful for NPS [21]. In Alzheimer's, for example, apathy may be due to hippocampal degeneration, rather than a reflection of an underlying depression. In fact, depression is a common prodrome to emergence of Alzheimer's dementia. There is also evidence that social interventions and dementia-specific medications such as ChEIs and glutamate antagonists decrease depression and anxiety [22].

Psychosis and aggression are common in those living with Alzheimer's disease and usually respond to certain antipsychotic medications. The standard of care recommends an informed consent discussion of risks, benefits, and alternatives to antipsychotic use as well as regular monitoring of NPS with a valid scale such as the NPI. Currently, the only antipsychotic medications supported by a large body of evidence are risperidone, aripiprazole, and in certain situations olanzapine [3].

Frontotemporal Neurocognitive Disorder

FD is a 62-year-old male who was brought into the emergency department after assaulting his son. His family reports the patient has been argumentative, disinhibited, and exhibiting very poor judgment. Last week, he set fire to a tree in his backyard and was threatened with arrest. His wife pulls you aside and whispers, "I think he has manic depression, but why would he get it at his age?"

Major frontotemporal NCD, formerly referred to as frontotemporal lobe dementia or degeneration (FTLD), refers to a number of syndromes characterized by frontotemporal lobar dysfunction in the absence of Alzheimer's pathology.

Frontotemporal NCD should be considered when (1) there is clinically detectable evidence of decline in one or more cognitive domain, (2) the disturbance has insidious onset and gradual progression, (3) there is relative sparing of memory and perception, and (4) the disturbance is not better explained by another process, such as cerebrovascular disease, another neurodegenerative disorder, substance use, or another mental, neurological, or systemic disorder [2]. Diagnosis of frontotemporal NCD also includes behavioral and language variants, which further complicates the diagnostic conundrum.

Neuropsychiatric Symptoms in Frontotemporal NCD

Characterized by progressive personality change, behavioral challenges, and impaired judgment and executive function, the behavioral variant of frontotemporal NCD generally involves a "fast and furious" decline. Attention and memory may be normal in frontotemporal NCD, which clouds the diagnostic picture. Further adding to diagnostic uncertainty is an early onset of symptoms, around age 40–60, which is far sooner than what is typically seen in other forms of NCDs.

Paranoia and delusions, particularly persecutory, as well as occasionally euphoria, are seen in mild-moderate frontotemporal NCD. Sleep disturbances and apathy are common in FT NCD. When the major FT NCD is moderate to severe, agitation, combativeness, disruptive motor, and vocalizations are all common.

Roughly 60 percent of all frontotemporal NCDs involve the *behavioral variant*, in which emotional dysregulation can cause mania that can mimic a bipolar disorder. It is not uncommon for individuals with the behavior variant form of frontotemporal NCD to present to the emergency department as floridly manic, with no measurable memory impairment. Further, many individuals with behavior variant frontotemporal NCD may develop obsessive or compulsive behaviors and fetishes, which also make diagnosis difficult. The behavioral variant of frontotemporal NCD was previously referred to as behavior variant frontotemporal lobe dementia (bvFTLD) and includes either (1) prominent decline in social cognition and/or executive abilities or (2) three or more of the following: (a) behavioral disinhibition; (b) apathy or inertia; (c) loss of sympathy or empathy; (d) perseverative, stereotyped, or compulsive/ritualistic behavior; or (e) hyperorality and dietary changes [2].

The *language variant* of frontotemporal NCD is characterized by language impairment, either in the form of speech production, word finding, object naming, grammar, or comprehension [2]. Under the umbrella of language variant frontotemporal NCD is another division, namely, fluent and nonfluent forms. Primary progressive aphasias (PPA) include progressive nonfluent aphasia (PNFA), which is characterized by slow, effortful speech, a semantic fluent aphasia (SFA) in which speech rate may be normal but the meaning of the words is lost, and logopenic progressive aphasia (LPA), in which the words themselves are lost. While a discussion of the various forms of language variant frontotemporal NCD is beyond the scope of this text, it underscores the wide variation in which an individual may present for care and the difficulty with diagnostic certainty.

Treatment of Frontotemporal NCD

Treatment is complicated in frontotemporal NCD. First-line treatment involves behavioral, environmental, and social interventions. There is no evidence of benefit from cholinesterase inhibitors. Glutamate antagonists also lack an evidence base supporting their use. Low-dose serotonergic medications can occasionally be helpful, but the majority of treatment is aimed toward mitigating behavioral symptoms. Mood stabilizers may be helpful in this regard if there is no response to behavioral, social, and environmental interventions. Psychosis and aggression usually respond to certain antipsychotic medications. The standard of care recommends an informed consent discussion of risks, benefits, and alternatives to antipsychotic use as well as regular monitoring of NPS with a valid scale such as the NPI. Currently, the only antipsychotic medications supported by a large body of evidence are risperidone, aripiprazole, and in certain situations olanzapine [34].

Consistent with other NCDs, the differentiation of major versus mild depends on whether the NCD has crossed the threshold of function. Also consistent with other NCDs, the designation of probable vs possible depends on evidence of causative frontotemporal NCD genetic mutation from family history or genetic testing or neuroimaging evidence of frontal and/or temporal lobe degeneration. Differences between NCD due to AD and frontotemporal NCD are portrayed in Table 3.2.

Neurocognitive Disorder with Lewy Bodies

LB is a 74-year-old retired grocery clerk. He was forced into retirement after repeatedly stumbling and falling at work. He has had several visits to the emergency department and is frustrated that he has not been given a diagnosis. He is anxious and dismayed when he presents to your office. After a bit of coaxing, he discloses that he has been seeing a little girl in a red apron standing at the end of his bed. "Please tell me I'm not crazy," he begs.

Table 3.2 NCD due to Alzheimer's disease vs frontotemporal NCD

NCD due to Alzheimer's disease	Frontotemporal NCD
Insidious onset, delusions, and memory impairment occur early in the disease	Fast and furious onset, problems with judgment and impulse control. Memory not impaired until late in the disease
Age of onset is late; 60–90 or later	Age of onset is early; 40–60
Language deficits involve word-finding difficulties	Language deficits may range from word-finding difficulties to nonsensical language
Mood is generally stable	May present as manic
Treatment with ChEI is beneficial	ChEI ineffective, may make things worse
Glutamate antagonist is generally beneficial	Glutamate antagonist not helpful

Neurocognitive disorder with Lewy bodies (NCDLB) is the most common neurocognitive syndrome associated with parkinsonism. Unlike Alzheimer's disease, which involves amyloid bodies, NCDLB is considered a tauopathy and is often overlooked pathologically because of the difficulty identifying cortical Lewy bodies.

Major or mild neurocognitive disorder with Lewy bodies should be considered when (1) there is clinically detectable evidence of decline in one or more cognitive domain, (2) there is insidious onset and gradual progression, and (3) the disorder meets a combination of core diagnostic features (fluctuating cognition with fluctuating levels of awareness, recurrent and detailed visual hallucinations, spontaneous features of parkinsonism that developed prior to the onset of cognitive decline) and suggestive diagnostic features (REM sleep behavior disorder, severe neuroleptic sensitivity). As with other neurocognitive disorders, the disturbance is not better explained by another etiology [2].

Neuropsychiatric Symptoms in NCDLB

Like other neurocognitive disorders, NCDLB is characterized by decline in cognitive and functional performance with deficits in attention and executive functioning. Unlike other NCDs, however, memory function may remain robust, and the initial symptom may be the onset of vivid hallucinations and delusional content.

Neurocognitive disorder with Lewy bodies is felt to exist on a continuum with Parkinson's-related disorders, so parkinsonism is a key characteristic in NCDLB. Specifically, individuals with NCDLB typically exhibit spontaneous motor features of parkinsonism, including slowed motor speed, shuffling gait, dyskinesia, masked facies, and tremor. The motor symptoms present later than other symptoms in NCDLB. Severe fluctuations and pronounced variation in alertness are also common, as well as frequent falls, syncope, autonomic dysfunction, and transient loss of consciousness. Language functions appear slowed, and visuospatial abilities are abnormal. NCDLB also has a high rate of depressive NPS.

Most individuals with parkinsonism exhibit neuroleptic sensitivity, so individuals with NCDLB also tend to be intolerant of moderately potent antipsychotics. For example, an individual with NCDLB or parkinsonism will likely develop increased muscle tone and tremor when prescribed neuroleptic agents, such as haloperidol.

NCDLB has other defining features that differentiate it from other types of NCDs. They may also have complex and well-formed visual hallucinations. For example, an individual with Alzheimer's-related hallucinations may describe them as "children playing in the hallway." In contrast, an individual with Lewy body-related hallucinations may experience them in greater detail, such as "a little girl wearing a yellow bonnet with an apple."

The onset of hallucinations is also different in NCDLB versus AD. Hallucinations are fairly rare in early Alzheimer's, tend to last days or weeks, and may be associated with an acute illness or delirium. In contrast, NCDLB-related hallucinations may last months or years in duration [21].

Additional features suggestive of NCDLB pathology include rapid eye movement (REM) sleep behavior disorder (RSBD), the onset of which may precede parkinsonism by a decade or more.

The progression of NCDLB is considered to be more rapid than Alzheimer's. If AD were to be visualized as a ball rolling down a hill, NCDLB would be seen as a ball bouncing erratically down a hill [28].

Treatment of Major Neurocognitive Disorder with Lewy Bodies

Neurodegeneration in NCDLB includes deficits in choline transmission; therefore, a ChEI is indicated. Because of the fluctuating nature of NCDLB, the use of a steady distribution agent such as a transdermal patch can be useful. For that reason, many individuals with NCDLB are tried on a rivastigmine patch. Interestingly, the hallucinations and delusions experienced by those living with NCDLB often respond robustly to ChEIs. If psychotic NPS are causing significant distress or dangerousness and do not respond to a ChEI, the addition of low-dose quetiapine or clozapine can be quite successful.

Glutamate antagonists can be helpful with NCDLB, although the evidence is mixed. It is worth noting that cholinergic deficiency in NCDLB is greater than that seen with Alzheimer's, so minimizing anticholinergic medications is particularly important.

Consistent with other NCDs, the differentiation of major versus mild depends on whether the NCD has crossed the threshold of function. Unlike other NCDs, however, family history is not a common prognostic factor in NCDLB. Genes have been identified that may point to a vulnerability, but there is little other criteria to assist in

Table 3.3 Alzheimer's vs. Lewy body

NCD due to AD	**NCD with Lewy bodies**
Insidious onset, delusions, and memory impairment occur early in the disease	More rapid onset; visual hallucinations may occur early in disease; memory may not be affected until later
Motor symptoms do not occur until later	Parkinsonism is a core feature
Neuropsychiatric symptoms such as visual hallucinations are common but tend to be vague and nondescript	Neuropsychiatric symptoms such as visual hallucinations are common, complex, and well-defined
Language may be impaired; word-finding difficulties	Language is slowed
Generally tolerant of antipsychotics	Generally intolerant of antipsychotics
Treatment with ChEI is beneficial	Treatment with ChEI is beneficial
Treatment with glutamate antagonist is generally beneficial	Treatment with glutamate antagonist may or may not be beneficial

the designation of probable vs possible NCDLB. Table 3.3 outlines differences between dementia due to AD and dementia due to Lewy bodies.

Neurocognitive Disorder Due to Parkinson's Disease

PD is an 83-year-old retired piano teacher. Slowly, almost painstakingly, she describes her sadness at no longer being able to play her beloved piano, due to the severity of her tremor. "Of course," she says, "I actually had to stop performing a few years ago, when I found that I couldn't keep up with the tempo. I tried to join a choir instead, but I sound like Kate Hepburn, and my voice is also thinner than it used to be. Do you think I am just depressed?"

Individuals with Parkinson's disease (PD) have an almost sixfold increase in prevalence of neurocognitive disorder, compared to those individuals without the disorder; however, the anatomic and pathologic basis of PDD (Parkinson's disease dementia) is not fully understood.

As above, PDD and NCD with Lewy body dementia are thought to exist on a continuum. Therefore, differentiating between PDD and NCDLB is based on history and what is referred to as the "1 Year Rule" [15, p. 2]. If the NPS precede the parkinsonian symptoms by 1 year, then the etiology is presumed to be NCDLB. If the parkinsonian symptoms precede NPS, then the diagnosis is most likely PDD.

Diagnostic criteria for PDD includes (1) documented decline from baseline, (2) disturbance occurs in the setting of established Parkinson's disease, (3) insidious and gradual progression of impairment, and (4) NCD is not attributable to another etiology. Probable NCD with PD is presumed when there is no evidence of mixed etiology and the PD precedes the onset of the NCD. Possible NCD with PD is assigned for individuals in which there may be a mixed etiology or the temporal relationship between diagnosis of PD and onset of NCD has been established. As with all other NCDs, the designation of mild versus major depends on whether the impairments affect functional outcomes [2].

Neuropsychiatric Symptoms in PDD

Unlike other neurocognitive disorders, the onset of PDD involves motor symptoms early in the disease. Motor signs may include tremor, stiffness, and gait instability. Attention and visuospatial function may be normal. Attention and language tend to be slowed. Affect is restricted or blunted. Executive functioning and thought processes will be slowed but may be normal. Depression is very common in PDD. Because PDD and NCDLB exist along a continuum, NPS commonly seen in NCDLB will also be commonly seen in PD, including depression, apathy, and vivid visual hallucinations.

Treatment of PDD

As with other NCDs, cholinesterase inhibitors may be helpful for those with PDD. Evidence on the utility of glutamate antagonists is mixed, as is similar to NCDLB. Cholinesterase inhibitors may help with visual hallucinations, paranoia, delusions, and other NPS in individuals with PD. Rivastigmine remains the best studied and only FDA-approved treatment for PDD, although some evidence supports the use of donepezil and galantamine [34].

As with NCDLB, individuals with parkinsonism tend to have neuroleptic sensitivity, so moderate to high potency antipsychotics should be avoided. Clozapine has the best data for reduction of visual hallucinations but is associated with serious side effects and requires active monitoring. Quetiapine is currently the most commonly used atypical antipsychotic in individuals with neuroleptic sensitivity due to better tolerability, although has less evidence to support relief of hallucinations, and may be overly sedating at higher doses [34].

Quetiapine has brief receptor occupancy, so low and frequent dosing is preferable. Quetiapine and carbidopa/levodopa have similar half-lives, so low doses of quetiapine given at the same time as carbidopa/levodopa can help mitigate carbidopa-induced psychosis.

Table 3.4 compares differences between NCD due to AD, Lewy body, and Parkinson's, and Table 3.5 helps differentiate between the main types of NCDs in terms of onset, cognitive domains, and treatment.

Neurocognitive Disorder Due to Huntington's Disease

Huntington disease (HD) is an inherited progressive neurodegenerative disorder characterized by choreiform movements, NPS, and neurocognitive impairment. The pathophysiology of HD is not fully understood, although it is thought to be related to toxicity of the mutant huntingtin

TABLE 3.4 AD vs NCDLB vs PD

NCD due to AD	NCD with Lewy bodies	NCD due to PD
Memory impairment occurs early. Delusions may occur early. Hallucinations occur later. Motor symptoms occur late.	Visual impairment occurs first, then motor symptoms. Memory may not be affected until later	Motor symptoms occur first, then visual hallucinations. Memory may not be affected until later.
NPS such as visual hallucinations are common but tend to be vague and nondescript	NPS such as visual hallucinations are common, complex, and well-defined	NPS such as visual hallucinations are common but less complex than NCDLB
Language may be impaired; word-finding difficulties	Language is slowed	Language is slowed
Generally tolerant of antipsychotics	Intolerant of antipsychotics	Intolerant of antipsychotics
Treatment with ChEI is beneficial	Treatment with ChEI is beneficial	Treatment with ChEI may be beneficial
Treatment with glutamate antagonist is generally beneficial	Treatment with glutamate antagonist may or may not be beneficial	Treatment with glutamate antagonist may or may not be beneficial

protein. Symptoms begin insidiously with movement abnormalities and/or with neuropsychiatric or neurocognitive symptoms. The course is one of slow but relentless deterioration in cognitive and motor function. There is currently no cure, and treatment is supportive and symptomatic [33].

Chorea is a key feature of NCD due to HD and the most salient symptom at the time of diagnosis. Chorea is a characterized by brief, abrupt, involuntary, non-stereotyped movements involving the face, trunk, and limbs [13]. These

Table 3.5 Differentiating types of NCDS

	Alzheimer's dementia	**Vascular dementia**	**Frontotemporal dementia**	**Parkinson's disease dementia**	**Lewy body dementia**
History/ onset	Insidious, presents *w*/depression, vague sx2–3 years before dx. Memory, language, visual-spatial problems, indifference, delusions, agitation	Hx of HTN, vascular disease, CAD, abrupt onset but may be insidious. Stepwise deterioration	Insidious, personality change, apathy, disinhibition	Motor signs precede dementia by at least 1 year	Prominent detailed visual hallucinations precede motor signs
Motor signs	Late	Motor signs, balance deficits, or hemiparesis	Apraxia, gait instability	Tremor, stiffness, gait changes	Parkinsonian signs; motor signs and dementia may occur in same year
Attention	Normal	Difficulty with mental tracking	Normal	AMS, marked fluctuation in alertness, attention	
Memory	Early: difficulty learning new info and retaining it	Decreased memory retrieval	May be normal	Slowed	Mildly impaired early

Language	Aphasia, anomia, decreased verbal fluency	Variable depending on lesion Most have prominent aphasia	Progressive nonfluent (logopenic) or fluent (semantic) aphasia	Slowed, dysarthria is common
Thought disorders	Delusions			Visual hallucinations and delusions
Visual spatial	Mild early and progressive	Variable, depending on lesion	Relative preservation of visual-spatial skills	Prominent visual-spatial abnormality
Mood, affect	Apathy, depression, personality change	Behavioral changes	Marked apathy, disinhibition, personality change	Apathy
Executive function	Mild early and progressive	More prominent than memory loss	Abnormal frontal lobe, judgment	Slowing of thought process impaired
Treatment	Start early with ChEl, add NMDA antagonist. Avoid anticholinergics	ChEl NMDA antagonist. Treat vascular risk factors	Low-dose SSRI helpful. Avoid ChEl; may worsen symptoms. Antipsychotic variable, can be helpful. Consider mood stabilizer	Avoid all neuroleptics except low-dose quetiapine or pimavanserin. Possible role for low-dose ChEl, rivastigmine patch best. NMDA antagonist variable, possibly unhelpful

movements are mild and may be misinterpreted as restlessness. Individuals may be unaware of the movements and may incorporate the chorea into purposeful actions, a phenomenon termed parakinesia, which can affect up to one half of all individuals with HD, thus complicating the diagnostic picture [20].

Neuropsychiatric Symptoms in HD

Cognitive decline is inevitable in HD. The dominant cognitive feature of HD is executive dysfunction with diminished ability to make decisions. Anosognosia into cognitive and motor impairment is common [23].

NCD due to HD is described as *subcortical*; meaning it refers to a clinical model of cognition that highlights frontostriatal pathways as facilitators of speed and efficiency of thought. Unlike cortical NCDs, such as those seen with Alzheimer's disease, individuals with NCD due to HD tend to do better with cueing, suggesting that memory problems are due to organization, rather than retrieval. Psychosis and motor symptoms in those with HD are treated with antipsychotics, usually haloperidol.

Injury-Related Neurocognitive Deficits

Vascular Neurocognitive Disorder

VD is a 92-year-old retired truck driver that has suffered a series of small strokes over the past several years. He has reached a plateau in rehabilitation, and his insurance will no longer authorize his recovery in a skilled nursing facility. He is described as apathetic and amotivational. He is sent to you for treatment of depression. You notice that his speech is slow, and he is passive with examination.

There are a plethora of names for cognitive deficits following a vascular event, including stroke-related dementia, multi-infarct dementia, and vascular dementia. A lack of uniform diagnostic criteria clouds the naming conventions; however, all refer to the onset of cognitive deficits associated with cerebrovascular disease. In the DSM-5, cognitive disorders for which cerebrovascular disease is the predominant, if not exclusive pathology, are referred to under the umbrella of major or mild vascular neurocognitive disorder. Major or mild vascular NCD is the second most common cause of NCD after Alzheimer's disease.

Diagnostic criteria for major or mild vascular neurocognitive disorder follow the same format as other NCDs: (1) there is clinically detectable evidence of decline in one or more cognitive domain; (2) clinical features are consistent with a vascular etiology that includes a temporal relationship to a cerebrovascular event or decline in complex attention, processing speed, or frontal-executive function; (3) there is empirical evidence of cerebrovascular disease from history, physical examination, or neuroimaging that is sufficient to account for the neurocognitive deficits; and (4) symptoms are not better explained by another etiology [2]. Evidence of injury on neuroimaging is generally combined with neurological deficits on examination to confirm the diagnosis.

Consistent with other NCDs, the differentiation of major versus mild vascular NCD depends on whether the NCD has crossed the threshold of function. As with other NCDs, the differentiation of probable vs possible depends on neuroimaging evidence of significant parenchymal injury due to cerebrovascular disease, a temporal relationship to a vascular event, or a combination of clinical and genetic evidence of cerebrovascular disease [2].

Neuropsychiatric Symptoms in Vascular NCD

In general, onset of vascular neurocognitive disorder is abrupt, followed by a stepwise deterioration. Motor and balance deficits may be prominent. Unlike other degenerative neurocognitive disorders, however, abnormalities in cognitive functioning will depend on the location of the vascular event or lesion.

Depression, apathy, and amotivation are common early neuropsychiatric symptoms of vascular NCD, owing to the common comorbidity of depression and cerebrovascular stroke. Hallucinations and other psychotic symptoms depend on the location of the lesion.

As you may recall, we conceptualized the trajectory of NCD due to AD as a ball rolling down a hill and NCDLB as a ball bouncing erratically down a hill. In the same manner, the visualization of vascular NCD would be a ball rolling down an uneven set of stairs [27, 28]. Deterioration tends to occur suddenly, in the context of a vascular event, followed by a period of stability, followed by another sudden drop due to a subsequent injury. As well, there are a significant number of people living with both AD and VD.

Treatment of Vascular NCD

Cholinesterase inhibitors are a cornerstone of treatment for vascular NCD. In general, higher doses of ChEIs are generally used for individuals with vascular neurocognitive disorder than other NCDs such as those due to AD. Unlike other NCDs, however, there is no clear role for glutamate antagonists in slowing down the disease process; however, they remain useful for mitigation of NCD-related NPS.

The most salient treatment for a vascular neurocognitive disorder is reduction of risk factors for a subsequent vascular event. Smoking cessation is vital, as is attention to high-risk comorbidities such as hypertension and diabetes. Reducing stroke risk is the single strongest factor in reduction of vascular NCD.

Psychosis and aggression are common in those living with VD and usually respond to certain antipsychotic medications. The standard of care recommends an informed consent discussion of risks, benefits, and alternatives to antipsychotic use as well as regular monitoring of NPS with a valid scale such as the NPI. Currently, the only antipsychotic medications supported by a large body of evidence are risperidone, aripiprazole, and in certain situations olanzapine [34].

Neurocognitive Disorder Due to Traumatic Brain Injury

Traumatic brain injury (TBI) is a leading cause of death and disability. Major or mild neurocognitive disorder due to TBI is caused by a severe and abrupt displacement of the brain within the skull, typically the result of an impact to the head. Specific criteria for major or mild NCD due to TBI include the following: (1) diagnostic criteria for major or mild NCD; (2) evidence of brain injury with one or more of the following, (a) loss of consciousness, (b) post-traumatic amnesia, (c) disorientation and confusion, and (d) neurological signs such as evidence of injury on neuroimaging, new onset of seizures, worsening of premorbid seizure disorder, visual field cuts, anosmia, and hemiparesis; and (3) a temporal relationship between the NCD and the TBI, either immediately or persistent after the acute post-injury period [2].

Neuropsychiatric Symptoms in NCD Due to TBI

Cognitive impairment varies, depending on the severity of the TBI. The term "concussion" is commonly used as a synonym for mild TBI but is formally defined as a trauma-induced alteration in mentation that may or may not involve loss of consciousness [1]. Individuals with mild NCD due to TBI may experience cognitive inefficiencies and difficulty performing daily activities but with less severity than individuals with MNCD due to TBI. Common features of MNCD due to TBI may include disturbance in emotional functioning, irritability, personality changes, physical disturbances, or neurological symptoms. Depression is a common comorbidity, which can worsen functional outcomes and compound difficulties with independent living and self-care [2].

There is evidence that repeated concussions can cause chronic traumatic encephalopathy, with increased severity and duration of mental status abnormalities after each incident [19]. The sequelae of TBI can cause cumulative neuropsychiatric deficits, chronic traumatic encephalopathy, cognitive impairment, and NPS such as personality changes, behavioral challenges, depression, suicidality, parkinsonism, and speech and gait abnormalities [36].

Treatment of NCD Due to TBI

Although there is a dearth of research on the use of cognitive enhancers for treatment of major neurocognitive disorder due to TBI, treatment options can be borrowed from similar NCDs. A history of TBI is a strong risk factor for development of NCD due to Alzheimer's disease. Additionally, the mechanism and trajectory of NCD due to TBI is similar to vascular neurocognitive disorders. Therefore, treatment recommendations center around promotion of NCD-specific medications, such as cholinesterase inhibitors and glutamate antagonists, as well as reduction of risk factors for subsequent injury.

Psychosis and aggression occur in those living with MNCD TBI and usually respond to certain antipsychotic medications. The standard of care recommends an informed consent discussion of risks, benefits, and alternatives to antipsychotic use as well as regular monitoring of NPS with a valid scale such as the NPI. Currently, the only antipsychotic medications supported by a large body of evidence are risperidone, aripiprazole, and in certain situations olanzapine [34].

Delirium

HD is a 75-year-old retired carpenter that was brought in to the emergency department for confusion. He is unable to remember his age, wife's name, or what he did for a living. He has *been described as "quiet and befuddled" by the day shift nursing staff, but the night staff describe him as "wild and wooly." He is currently picking at unseen items on his bedclothes. His wife mentions that he made a hole-in-one on the golf course on Sunday.*

No description of NCD would be complete without reference to one of the major confounders when diagnosing dementia: delirium. Delirium can be misinterpreted as dementia, due to presentation in various stages of arousal, which complicates the diagnostic process. Derived from the Latin term meaning "off the track", delirium refers to a transient global cognitive disorder or group of symptoms associated with complex medical comorbidities. Defining characteristics include disturbance in attention and awareness that develops acutely and is characterized by fluctuation [18]. Delirium should be considered when there is evidence of (1) disturbance of attention and awareness; (2) acute onset, with fluctuating severity; and (3) disturbance in cognition, such as memory, disorientation, language, visuospatial ability, or perception; (4) the disturbance is not explained by another neurocognitive disorder or occur in the context of a severely reduced level of awareness, such as a coma; and (5) there is empirical evidence, such as physical exam or diagnostic data, that the disturbance is caused by a physiological condition, such as a medical etiology, substance intoxication or withdrawal, exposure to a toxin, or due to multiple etiologies [2].

Forms of Delirium

Three forms of delirium are described in the literature: hyperactive, hypoactive, and mixed. The *hyperactive* form of delirium often presents with psychomotor agitation and a plethora of psychiatric symptoms, such as confusion, hallucinations, or delusions. The hyperactive form is the most recognized form of delirium and is associated with perceptual disturbances and delusions in more than 70 percent of sufferers [4]. In contrast, the *hypoactive* form of delirium may mimic a stupor or coma and occurs more commonly than the hyperactive form. Hypoactive delirium has a higher mortality rate than hyperactive delirium, largely due to the effects of immobility [27]. Often called "quiet" delirium because it is characterized by a flat affect or apathy and often present in otherwise calm and seemingly alert patients [35], this type of brain dysfunction carries a grimmer prognosis than hyperactive delirium and is the most commonly missed subtype of delirium. The *mixed* form of delirium is the most frequent subtype of delirium and presents with both hyperactive and hypoactive features. It is not uncommon for delirious individuals to have daytime somnolence, accompanied by nocturnal agitation and insomnia. Alternatively, individuals may fluctuate between the hyper- and hypoactive forms during the course of a few hours.

Delirium accelerates the pace of underlying cognitive decline. It is not uncommon for the presence of an underlying neurocognitive disorder to "declare itself" after an episode of delirium [27, 28]. Although delirium may mimic other neurocognitive disorders, delirium is a separate syndrome and differs from other NCDs in key areas, including onset of symptoms and attention. The most important distinction between delirium and other NCDs is the potentially reversible attribute of delirium. Unlike most NCDs, which are chronic, progressive, and ultimately fatal trajectories, delirium is an abrupt onset of confusion with an optimistic rate of reversibility. With aggressive treatment of underlying causes, it is possible to return the individual to his or her pre-delirium baseline.

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Chapter 4

Evaluating Cognition and Performance Through Cognitive Domains

Sarah E. Foidel

Evaluating and Defining Cognition

Evaluation of cognition is a challenging and complex task. Humans are dynamic beings making cognition a multifactorial and environmentally dependent system. Disciplines lack consistent structure for assessment or a language to describe cognitive functions. Multiple models exist to examine at cognition. The multiple deterrent model considers biologic, environmental, cultural, and emotional factors when assessing cognition [5]. Traditional psychological testing looks at skill-based components as separate parts. Skill-based results are compared to normed samples to determine diagnostic significance. These skills traditionally include forms of attention, short-term and long-term memory, executive functioning, visual-motor skills, awareness, and reasoning. However, there lacks a consistent usage of language between researchers and clinicians. Professions such as nursing, social work, and medical physicians often rely on interview-based

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assessment and lean heavily on caregiver reports. While providing a holistic picture of a client's cognition by including cultural and environmental influences, such evaluations are subjective and rely heavily on social norms and language. For example, a patient with mid-stage Alzheimer's disease may retain enough language and social patterns to appear cognitively intact during a 15-minute primary care interview. Occupational therapy, focused on functional cognition, examines cognition through performance-based testing. However, evaluation using performance-based tests has minimal standardization and is subjective to rater bias [4]. By measuring cognition within task performance, a clinician can identify the influence of individual skill, environment, and activity demands during a real-world example [3]. In addition, a skilled therapist is required to rule out if motor symptoms are impacting functional performance.

Assessment of cognition is either skill-based or performance-based. Traditional skill-based tests look at individual cognitive abilities and generally compare scores to normed standards. Skill-based tests can be accurate for determining diagnosis, yet do not accurately predict function [4]. By looking at the guidelines for diagnosing neurocognitive disorders in the DSM-5, the main difference between minor and major neurocognitive disorders is a functional loss of the ability to independently complete daily activities [1]. The guidelines for differentiating between major and minor neurocognitive disorders are illustrated in Table 4.1, Diagnostic Criteria DSM-5 [1]. By establishing a need for an interdisciplinary assessment including objective evidence of skill-based assessments, subjective report of cognitive changes, and evaluation of functional performance, professionals must work together to create a person-centered evaluation.

Functional Cognition

Functional cognition involves the integration of multiple cognitive skills and includes problem-solving, motivation, personal priorities, and the ability to utilize strategies for

Table 4.1 Diagnostic Criteria DSM-5

Disorder	Criteria	Typical professionals involved in assessment
Neurocognitive disorder	Main deficits are in cognition One or greater cognitive domains show impairment Not developmental Decline from baseline Requires concern and clinical evaluation Decrease in everyday activities.	Psychiatrist Neurologist Primary care Physician Physician assistant Nurse practitioner Psychologist Qualified mental health practitioner
Differential diagnosis	DSM-5 Criteria	Typical professionals involve in assessment
Delirium	Impairment in attention Related to a physical cause Short and rapid onset; fluctuating cognition	Nurse Psychiatrist Hospitalist Nurse practitioner Physician assistant
Minor neurocognitive disorder	Measurable cognitive decline from a baseline Subjective report of mild decline Objective (cognitive screening) of mild decline Impairments do not interfere independence in everyday activities Rule out other mental health diagnosis and delirium	Neuropsychologist Psychiatrist Speech pathologist Occupational therapist

(continued)

Table 4.1 (continued)

Major neurocognitive disorder	Significant cognitive decline from a previous level of performance Subjective report of cognitive decline Objective report of decline (cognitive screenings) Decrease of independence in everyday activities Rule out other mental health diagnosis and delirium	Occupational therapist Nurse Social worker

Adapted from DSM- 5 Criteria [1]

cognitive challenges. Functional cognition is the overall outcome of cognitive skills working together. In natural environments, distractions, change in schedule, and error correction demand heavy use of executive function and higher-level cognitive skills including generalizations, abstraction, and problem-solving [6]. Motivation also plays a key role in task participation. The use of these metacognitive strategies has been found to enhance occupational performance by reducing task error and encouraging self-assessment and monitoring. Strategies have also been shown to enhance attention, memory, language deficits, and social skills [2, 43]. Personal utilization of strategies and skills can lead to improved functional outcomes. Although skill assessment is essential to identifying underlying type of cognitive impairment, it is not a reliable way to predict ability to successfully complete daily activities. Specifically, a standardized cognitive screening may indicate the need for neuropsychological testing to identify mild neurocognitive disorder; it will not assess safe ability to complete activities of daily living (ADLs) or instrumental activities of daily living (IADLs). A practical example includes the difference between identifying the ability to answering hypothetical safety questions on a test (What

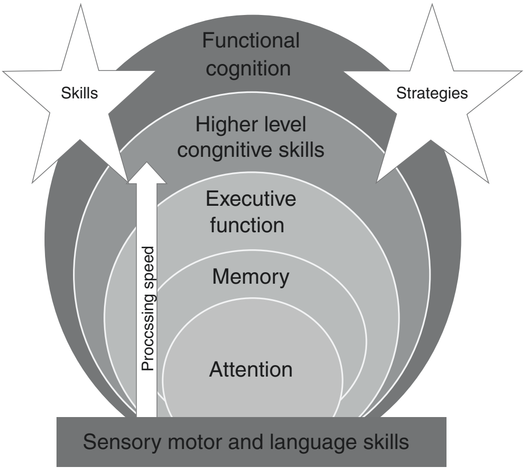


Figure 4.1 Model of skill hierarchy and functional cognition. (Original Figure created by Sarah Foidel for this text, 2018)

would you do if your house was on fire?) and the ability of a person to actually take safe action during an emergency. In this situation, the role of strategy development, environment, and processing speed with distractions is key to survival. Functional cognition can be defined as a measure of ability to perform everyday activities within a natural context [41].

As seen in Fig. 4.1, the model represents the hierarchy of cognitive skills proposed in this chapter. While accurate sensory information and language processing are necessary to understand information input, attention remains a prerequisite skill for other cognitive skills. The outcome is the ability to negotiate and succeed in everyday activities.

Cognitive Domains as Defined by DSM-5

The DSM-5 provides definition of six cognitive domains that can be used to guide clinician's assessment of neurocognition [1]. Traditionally, cognitive screenings rely heavily on memory and language skills. Instead of looking primarily at language and memory during cognitive testing, assessment of the additional domains should also be differentiated by the assessing clinician. Both top-down assessment (performance-based assessment, caregiver reports, skilled functional task observation) and bottom up tests (tests of attention, memory, awareness, and executive function) should be used in combination to clearly assess a person's level of neurocognitive impairment.

The six domains defined by DSM-5 include complex attention, executive functioning, learning and memory, perceptual-motor, social cognition, and language [1]. Evaluating each area for skill loss dictates clinicians have a clear understanding of assessment tools that target each domain. Also, differentiating between minor and major impairments in these domains impacts diagnosis. The following sections provide specifics of each domain, screening tool examples, and functional observations. In additional, a case study will highlight conditions with specific skill loss (Fig. 4.2).

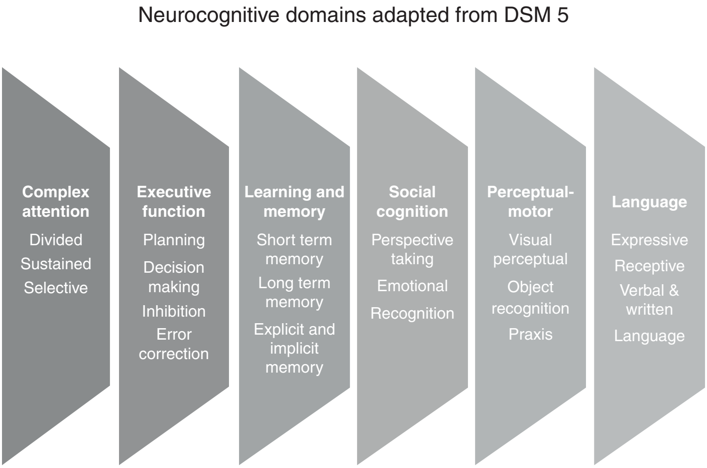


Figure 4.2 DSM-5 cognitive domains. (Original Figure created by Sarah Foidel for this text, 2018. Criteria adapted from DSM-5 Criteria [1])

Cognitive Domain: Complex Attention

Attention is a fundamental skill for survival. Based in the prefrontal cortex, how and to what attention is paid directly impacts the ability to use all other cognitive domains. A basic example is if minimal attention is given to information, it cannot be stored in explicit memory structures, utilized to demonstrate new learning, and applied in decision-making. Attention is a complex system involving arousal and vigilance. It varies in efficiency throughout the life span [8]. Visual attention, executive attention, and vigilance networks have all been identified as an interwoven set of attentional systems that impact a person's selection of relevant and not relevant information [16]. Key structures include the visual system, thalamus, prefrontal cortex, and right parietal cortex. It is also important to recognize the primary sensory cortex because the postcentral gyrus receives sensory information that impacts how the attentional systems are alerted. The limbic system likely connects emotions or implicit memory of important sensory information that may strongly influence the attentional networks.

DSM-5 identifies *divided attention*, *sustained attention*, *selective attention*, and *processing speed* as primary areas of the complex attention cognitive domain [1]. Selective attention is defined as attending to one stimulus when competitive information is available. Sustained attention is defined as maintenance of attention over time, processing as speed of completion simple task completion, and divided attention as paying attention to multiple tasks [1]. However, much discussion exists regarding true divided attention versus the skill of attentional switching. Attentional switching requires quickly shifting attention between two tasks without losing track of either task. A clinician must be aware of motor and sensory influences on the attentional network during screening for attention system, to avoid falsely identifying attentional difficulties. Examples of screenings for attention are included in Table 4.2, assessment of attention, as well as differential information between minor and major neurocognitive impairment. These factors include but are not limited to low vision, tremors, bradykinesia, cortical blindness, decreased strength, and motor apraxia.

Table 4.2 Assessment of attention

Example screening tools	Functional observations	Minor versus major (per DSM-5 Criteria)	Example conditions that impact attention
Trail Making A Trail Making B Registering words Moss Attention Rating Scale Test of Everyday Attention Months Backwards Test Serial sevens Scanning activities Consider delirium scales/screenings	Distraction mid-task Failure to register multistep commands Loosing track of conversation Needing frequent verbal cues Missing details Incomplete or inadequate hygiene Difficulty with math Difficulty scanning systematically	*Minor*: Normal tasks take longer; errors occur in procedural or everyday tasks Concentration more difficult with competing stimuli *Major*: Observable slowed thinking, inability to do calculations, easily distracted	Traumatic brain injury Frontotemporal lobe dementia Mania Attention deficit disorder Delirium

Diagnostic Criteria adapted from DSM-5 [1, 26, 29]

It is important that the clinician addresses attention as the first part of cognition evaluation. A person that cannot pay attention will perform poorly on all other cognitive screening items (see Figure 4.1: model of functional cognition). Not all attentional disorders fit the category of neurocognitive disorders, as deficits in the ability to attend are often seen in a number of different affective and developmental conditions.

Cognitive Domain: Executive Function

Executive functioning includes initiation, planning, error correction, and termination which occur during daily activities. Generally thought of as being housed in the frontal lobes, it is likely that executive functioning is also very dependent on memory, perception, and timing. Key structures include the prefrontal cortex with connections to limbic system and basal ganglia. The prefrontal cortex integrates information from sensory and motor circuits of the brain and navigates decision-making and responses to situations [16]. Flexibility of thinking, inhibition, planning, impulse control, and abstract thinking are all related to executive functioning. The skills of *initiation*, *error correction*, *inhibition*, *and termination* are commonly described as executive functional skills.

People struggling with executive function loss can present in many fashions. Common signs include poor social awareness, decreased recognition of errors, being overly agreeable, decreased follow-through (sometimes labeled as noncompliant), demonstrated IADL performance deficit, and change in relationships. As seen in Table 4.3, functional observations of executive function impairment vary greatly. Often overlooked by casual observations, many signs can be viewed as procrastination, laziness, and poor follow-through with daily activities. More severe executive functioning can present as apathy and poor ADL performance, passivity, repetitive behaviors, and impulsive speech.

DSM criteria include planning, decision-making, working memory, responding to feedback, error correction, inhibition, and mental flexibility [1].

TABLE 4.3 Assessment of executive function

Example screening tools	Functional observations	Minor versus major (per DSM-5 Criteria)	Example conditions that impact executive function
Frontal Assessment Battery Exit 25 Executive Function Performance Test Wisconsin Card Sorting Tests of abstraction Clock Drawing Test Picture search for hazards	Poor termination of activity (perseveration) Poor organization of steps Poor follow-through with planned activities Layering clothing Using too little or too much of supplies "Messy" or disorganized self-care Unable to anticipate challenges or fix mistakes	*Minor*: Increased effort for multistep tasks, limited ability to work on more than one thing at a time. Task organization causes fatigue. Struggles with planning and decision-making. Avoidance of large social situations due to fatigue *Major*: Abandons complex projects. Dependency in IADLs; limited to one-step activities	Frontotemporal lobe dementia Mania Attention deficit disorder Alzheimer's dementia

Diagnostic Criteria adapted from DSM-5 [1]

Learning and Memory

The process of storing and retrieving information that is brought into the sensory system is a network known as memory. People have a variety of memory types, both implicit and explicit. Explicit memory starts with attention to a stimulus and involves immediate, short-term, and working memory. Many theories of memory storage exist including how information is prioritized or chunked into meaningful information for storage. Primary structural areas include the inferolateral and medial temporal lobe [45]. Memory storage and learning are dependent on intact sensory information retrieval and attention.

DSM-5 Criteria include immediate memory, recent memory, long-term memory, and implicit learning [1]. Interestingly, procedural memory and motor planning impairment are included in the cognitive domain of perceptual-motor. As seen in Table 4.4, functional implications of memory loss include anxiety in new places, failure to complete household tasks, and asking repetitive questions. Memory loss causes decreased work, self-care, and social participation.

Cognitive Domain: Social Cognition

The domain of social cognition involves a person's ability to demonstrate self-awareness, negotiate relationships, have empathy, and understand the perspectives of others. Primarily housed in the frontal lobes, it can be thought of as the *human* part of our brain. Key structures include frontal lobe, including both dorsolateral and orbitofrontal prefrontal cortex. Both areas have direct impact on personality. Orbital frontal damage can result in impulsive and disinhibited behavior, while dorsolateral damage can result in an apathetic presentation [16]. The domain of social cognition is a unique addition to assessing cognitive abilities and allows a clinician to measure personality changes and the unique interpersonal challenges that greatly impact caregivers and people living with neurocognitive disorders. Formal assessments of social cognition often overlap with tests of executive functioning and, as detailed in Table 4.5, are

Table 4.4 Learning and memory

Example screening tools	Functional observations	Minor versus major (per DSM-5 Criteria)	Example conditions that impact memory
SLUMS MMSE MoCa Cognistat Rivermead memory RBANs Recalling words	Repeated stories Getting lost Trouble driving Not paying bills Anxiety in new environments Unable to keep work schedule	Minor: Decreased ability recalling recent events, reminders, making lists, or needing to rereading to keep track of new information. Occasionally may repeat self. Over a few weeks to the same person. Decreased ability to remember if bills are paid, appointments, etc. Major: Repeats self within a single conversation. Requires frequent reminders to orient to task during activity Needs assistance with IADLs	Alzheimer's dementia Traumatic brain injury Anoxic brain injury CTE

Table 4.5 Social cognition

Example screening tools	Functional observations	Minor versus major (per DSM-5 Criteria)	Example conditions that impact social cognition
Limited formal tools for adults – generally behavioral observation during interview and other formal screenings	Interrupting others Cursing Inability to recognize social norms (standing to close, eye contact – often culturally dependent) Inability to follow modeling of social behavior Lack of ability to understand impact of actions on others Low frustration tolerance	Minor: Decreased ability to recognize social cues and demonstrate empathy Change in social habits Disinhibition Episodic apathy Major: Behavior out of social norms and shows insensitivity in social situations Perseveration on topics Behaviors show no regard to others No safety awareness or insight into behavioral changes	Frontotemporal lobe dementia Huntington's disease

usually based on interactions between clinician and person with dementia. Careful assessment to clarify changes in baseline is important to consider when looking for deficits in the social cognition domain. DSM-5 Criteria published in 2013 include recognition of emotions, theory of mind, and the ability to understand the feelings of others in social cognition.

Cognitive Domain: Language

The cognitive domain of language is a set of abilities that allows a person to connect to other human beings. Language is not limited to words; it includes both expressive and receptive language skills. Often thought of as left hemisphere (or dominant hemisphere) dependent, the domain of language is dependent on both right and left frontal lobes, as well the temporal lobe for auditory processing and the cerebellum for timing. Primary expressive speech areas include the left inferior frontal gyrus, known as the Broca's area. In addition, in the right frontal lobe the area of prosody is located which controls the musical aspects of speech, understanding of affect and vocal tone, to allow a person to understand the unspoken aspects of speech [16, 46].

DSM-5 includes impairments in expressive language and receptive language [1]. It is important to note that language is more than just words and includes gestures, grammar, and the way words are put together to make a message. Table 4.6 includes common screening tools that include language items. In addition, clinicians must appreciate that most assessment tools heavily rely on language to measure other cognitive domains.

Cognitive Domain: Perceptual-Motor

The cognitive domain of perceptual-motor is an inclusive category that looks at the full extent of both motor and sensory portions of the central nervous system. It examines sensory perception as an important element of cognition. Primary processing areas are global including cranial nerve function and primary sensory areas (postcentral gyrus), as

TABLE 4.6 Language

Example screening tools	Functional observations	Minor versus major (per DSM-5 Criteria)	Example conditions that impact language
MoCa MMSE SLUMs Aphasia Diagnostic Profiles Boston Diagnostic Aphasia Examination Western Aphasia Battery Verbal expression of information Identifying familiar objects with language Following direction	Searching for words Inability to understand directions Loss of nouns during conversation Inability to read or write for IADLs Inability to understand change of affect Decreased symbol recognition	Mild: Observable word-finding difficulty Often uses general terms and has speech errors; may emit or incorrectly use articles, verbs, or prepositions Major: Difficulties with expressive/receptive language Uses non-specific nouns Often unable to recall names, grammatical errors. Echolalia, automatic speech, and possible mutism	Frontotemporal lobe dementia Primary progressive aphasia Primary nonfluent aphasia Vascular dementia and CVA (particularly R/L middle cerebral artery)

well as perceptual areas of the parietal lobe. Often seen after an acquired brain injury, perceptual-motor deficits can result in sensory and awareness impairments.

DSM-5 Criteria include visual-constructional skills, perceptual-motor, praxis, and gnosis (American Psychiatric Association). Skills include perception of space, motor planning, and object recognition. This unique domain, described in Table 4.7, includes cortical visual skills which may impact object recognition, categorization, and visual-spatial recognition. With the inclusion of this domain, people with significant topographical orientation impairment, driving difficulties, and difficulty initiating procedural motor tasks can be identified with the diagnosis of a neurocognitive disorder. Visual-perceptual skills include figure-ground recognition, visual closure, and visual memory which can have impacts to reading, writing, and negotiating new environments.

Conclusion

Assessment of neurocognitive disorders is a complex and dynamic task. Human cognition is heavily influenced not only by cognitive skill ability and baseline intelligence but by acquired strategies, environmental supports, and motivation. Using a model that considers the umbrella of functional cognition while also evaluating skill-based tests for challenges and opportunities, an interprofessional team can create a holistic and accurate picture of function. By examining interactions with real-life tasks, safe discharge planning and real-life abilities can be identified. Strength-based care plans correctly identify interventions that match person-centered abilities and create activities that facilitate meaningful relationships with the world. In 2014, the Joint Commission implemented voluntary memory care recommendations to increase person-centered care for people with neurocognitive disorders that included care coordination, increasing staff knowledge, ability-based activity programming, and behavior management that utilized non-pharmacological strategies [7]. By creating a holistic

TABLE 4.7 Perceptual-motor skills

Screening tools	**Functional observations**	**Minor versus major (per DSM-5 Criteria)**	**Example conditions that impact perceptual-motor**
Motor-Free Visual Perception Test Visual screenings Cranial nerve screenings Tests of visual-motor Copying designs Picture identification	Trying to sit on objects that are not there Getting lost Dressing apraxia Difficulty with copying and drawing tasks Undershooting and overshooting Missing the chair when sitting Poor spatial awareness Difficulty with visual-spatial skills – visual closure, figure-ground, form constancy	Minor: Shows reliance on maps or notes to find new places May get lost when not concentrating Driving or parking difficulties. Spatial tasks take effort	CVA TBI Parkinson's disease Alzheimer's disease Lewy body dementia

and interprofessional assessment system, care plans can be created that directly address individual ability and increase staff coordination of care. In addition, opportunities for regular staff education to increase understanding of cognitive domains and the impact impairment has on function can increase the quality of care.

Case Study: Allison

Allison, a 66-year-old woman, is hospitalized with pneumonia. Allison has a history of working as an administrative secretary for the last 20 years. She owns her own home and drives her own car. She loves cooking and painting.

She currently presents with depression as evidenced by decreased interest in leisure and self-care which has resulted in decreased strength, poor hygiene, and a 30-pound weight loss. Family reports she spends a majority of her time in a porch swing, will only eat minimally, and has had a 5-year history of depression (resulting in early retirement). After treating her pneumonia, she is transferred to the psychiatry unit.

According to Allison (narrative):

- Limited concern about loss of employment retirement
- Reports still liking crafts, shrugs shoulders about how often
- Reports she cooks and completes ADLs independently
- Poor ADL/ hygiene observed
- Unconcerned about weight loss

Additional information provided by family:

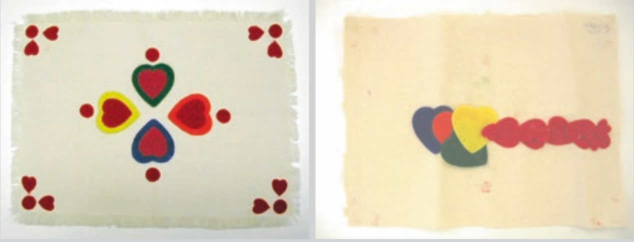
- Nutritional changes are more bizarre in nature
- Reports quality of food prep and crafts have decreased

- Repetitive behaviors noticed
- No traditional signs of hopeless, helpless, or poor self-worth (typical of depression)

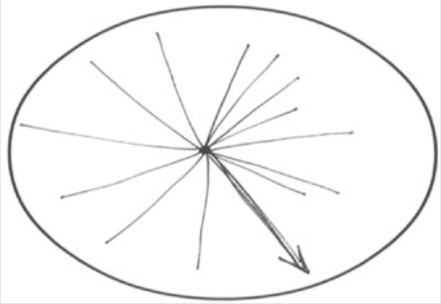
Activities of daily living screening:

- Maximum cues for completion
- Perseveration
- Washing face six times
- Refusing toothpaste
- Fills pants with toilet paper
- Non-directable with verbal cues to alter focused behavior

The following were screenings completed:
by Allison



Allen Diagnostic Module: Place mat at score 3.6 [44]



Images by Foidel 2018

Assessments: Severe executive functioning impairment (sequencing and termination on Clock Drawing Test; Allen Diagnostic Module indicates loss of goal-directed activity and perseveration; craft observation shows significant perseveration).

Diagnosis: Frontotemporal lobe dementia, behavioral variant

Reason: Personality change, disordered social conduct, and loss of insight. Poor hygiene or apathy is common. Mistaken for mania or depression at times. Late in illness speech may become terse and stereotypic. Apathetic presentation.

Primary cognitive domains impaired: executive functioning and social cognition

Treatment planning considerations:

- Recognize and correctly “label” behaviors
- Adapt environment to promote ADL completion
- Assist in providing information to clarify diagnosis
- Recognize memory and orientation may be more intact than social/language skills
- Identify appropriate communication techniques (reality orientation vs. validation/distraction)
- Educate family and caregivers
- Set realistic goals

Below is a sample assessment looking at both skill-based assessment and functional observation to create a strength-based care plan for an individual with major neurocognitive disorder, Alzheimer's type. Because of the advanced nature of the illness, this evaluation was created by an occupational therapist. The assessment is informative and person-centered and benefits the entire interprofessional team.

Functional Assessment for Strength-Based Care Plan by Occupational Therapy

JS is an 84-year-old woman with the history of a high school education and positive social relationships. Worked as cafeteria lunch lady and a homemaker. Four children, three are local and visit on a regular basis. Hobbies are gardening and baking. Hates TV. Loves to read. Catholic.

Diagnosis: Alzheimer's dementia

Main neuropsychiatric concerns: Anxiety, wanders Risk

ADL performance: Independent ambulation, forgets to complete ADLs (requires supervision) *PMH*: N/A

Cognitive domain	Strengths	Mild impairment	Major impairment
Complex attention	Focused with cues × 30 minutes on interview; participated in full evaluation		

Executive function			Decreased performance on CDT; poor oral word association; 4.0 on ACLS
Learning and memory			0/3 short-term memory; repeated stories
Social cognition	Affect congruent; able to express concern for social situations; able to introduce self and tell life story		
Perceptual-motor		No sensory loss, full object recognition, mild constructional apraxia. Poor topographical intervention. Mild ideational apraxia	
Language		Mild anomia; uses vague nouns. Able to name 8/10 familiar objects	

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Summary of Strengths

JS retains a conversational memory skill and is able to perform two-step LTM tasks with setup and cues. Retains object recognition skills (recognizes familiar tools, signs, and ADL tools). Strong ambulation skills. Reports no pain; no observable signs of pain during functional tasks. Recognizes family. Follows modeling for task completion and searches out social participation.

Summary of ADL Function

Setup required for hygiene (grooming, teeth brushing, hair combing). Able to complete in standing with cues to initiate. Dressing independent. Benefits from cues to use the restroom after meals and before bed, cannot find location of bathroom without assist. Independent in clothing management. Shower minimum assist (setup, assist with hidden areas).

Recommendation for Activities:

- One-step gardening activities (trimming flowers, arranging flowers in vase, deadheading plants, planting from pot to soils, snapping beans, husking corn, labeling plant markers, destemming strawberries). Familiar environment will support participation, such as wearing gardening gloves, being in outside garden, and completing tasks in a groups that provides physical modeling.
- Memory sharing and reminiscence (provide familiar items, train staff to ask context oriented questions, LTM trivia).
- Daily exercise in group (stretches, chair exercises, walk in the garden).

Recommendation for caregiver education: Grading activities for success, reminiscence facilitation, communication

Date for review: Functional observations and assessment of participation in 2–3 months to identify care needs

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Chapter 5
Behavioral Interventions for Those Living with Dementia

Sarah E. Foidel

Overview of Behaviors

In looking at behavioral interventions for people with major neurocognitive disorder, dementia, it is difficult to separate personal experience from published research. Despite limited evidence to support long-term behavior changes with the use of nonpharmacological interventions in dementia, evidence does support caregiver training for improving targeted behaviors. Person-centered care planning must be considered when choosing interventions. Special consideration will be given to techniques that promote activities of daily living participation to decrease caregiver burden. In addition, focusing on individual preference and understanding personal history are essential to the person-centered care model.

Alzheimer's disease and other dementias are growing by epidemic proportions in the United States. As of 2018, Alzheimer's was the sixth leading cause of death with over 15 million unpaid caregivers supporting this incurable disease [1]. One in three seniors will die with a dementia condition

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[1]. Despite being known for cognitive loss, dementia has significant behavioral challenges that increase as the disease progresses. Current research indicates 60–80% of people with dementia present with neuropsychiatric symptoms which are the largest burden on care providers [5]. During the course of the disease, aggression, depression, restlessness, and delusions are common [9, 13]. Neuropsychiatric symptoms (behaviors) are defined in many ways. The Neuropsychiatric Inventory (NPI) categorizes these behaviors as delusions, hallucinations, agitation, depression, anxiety, euphoria, apathy, disinhibition, motor disturbance, nighttime behaviors, and appetite changes [8]. Table 5.1 describes the NPI's definition of behavioral disturbances in behavioral terms for caregivers.

Many scales exist to stage dementia. The DSM-5 defines neurocognitive disorder as minor or major, with major neurocognitive disorder being synonymous with the term dementia. Functional loss in everyday activities defines the difference between diagnosing minor and major neurocognitive disorder [2]. National Institute on Aging task force recommendation also includes using loss of function to mark later stages of the disease [21]. Functional impairments include language loss, decreased occupational engagement, and observable loss of self-care function [21]. Apraxia, aphasia, and agnosia are all common in late stage dementia. Apraxia is defined as a motor planning deficit, often present after a CVA or damage to the frontal lobe. People with apraxia demonstrate difficulty carrying out procedural steps of a task without other motor or sensory deficits. Aphasia, due to damage in frontal or temporal lobe of the left hemisphere, refers to receptive or expressive language. Gnosia, object recognition, is a cortical visual skill. Agnosia refers to person with dementia's loss of object recognition. Because of severe functional and cognitive loss, engagement in meaningful activities and self-care becomes more difficult. However, caregiver support and environmental changes have shown to significantly reduce

TABLE 5.1 Neuropsychiatric Inventory definition of behaviors

Neuropsychiatric symptom	Defined by NPI	Frequent observation
Delusions	False beliefs	Scared of partner cheating Kids stealing money
Hallucinations	False visions	Seeing people or pets others cannot see
Agitation	Resistive to help	Uncooperative with self-care
Depression	Demonstrates sadness	Reports feeling sad; acts sad
Anxiety	Upset with separation; signs of nervousness	Unable to relax even during enjoyable activity
Euphoria	Too happy	Excessive silliness that is not congruent with context
Apathy	Less interested in normal activities	No enjoyment of activities that are meaningful
Disinhibition	Impulsive or inpatient	Says angry things; hurts people's feelings
Motor disturbance	Repetitive activities	Layers clothes, perseverates activities (does steps over and over)
Nighttime behaviors	Poor sleep pattern	Gets up early, wakes up early
Appetite	Weight gain or loss	Change in food preferences or patterns

Adapted from NPI scale [8]

behaviors and delay placement outside the home [29]. A review of nonpharmacological interventions indicates that responses to direct sensory, cognitive, and emotional supports all need additional evidence and have limited long-term effects on disease reduction of challenging behaviors [18, 24]. Evidence relating efficacy of nonpharmacological interventions to improve quality of life specifically in people with severe dementia is significantly limited [7]. Due to safety concerns and despite limited evidence, nonpharmacological interventions are recommended prior to using pharmacology to decrease neuropsychiatric symptoms [13]. A 2018 systematic review of nonpharmacological interventions found that functional-based interventions should be used as first-line management of behaviors [12]. Neuropsychiatric symptoms often lead to challenging behaviors. Without caregiver training, attempting interventions can lead to poor outcomes and decreased cost-effectiveness for people with dementia [23]. Cohen-Mansfield and colleagues demonstrated that many doctors and nurse practitioners need additional education and resources to appropriately recommend and explain nonpharmacological interventions [6]. Due to the frequent turnover in caregiving staff, education is often seen as an expensive option for interventions. However, in 2017 study, data suggest that caregiver participation in a behavioral interventions does not increase may actually decrease costs of care [22]. Evidence suggests the need for additional practical education by providing behavior-specific interventions to enhance the quality of life for people with moderate-severe dementia and their caregivers.

Interventions in Major Neurocognitive Disorder

Advanced, moderate-severe, dementia is defined by the loss of ability to engage in routine activities and decreased ability to complete self-care [18]. Specifically, advanced dementia is marked by loss of language, incontinence, poor sequencing activities of daily living, and disinhibited behavior [4]. However, homogeneous sample studies that relate only to major neurocognitive disorder are extremely limited. Traditionally, dementia studies include people with mild, moderate, and severe dementia which increases the heterogeneity of the sample [29]. In addition, because dementia is an umbrella term for many conditions, participants in each study may have a varying types of brain damage. Kverno et al.'s [18] systematic review of nonpharmacological interventions in dementia discovered that out of 215 dementia studies, less than 10% focused on advanced dementia.

As shown in Table 5.2, behavioral interventions are divided into emotion-oriented interventions, sensory-oriented interventions, and environmental adaptions. Due to severity of illness, cognitive-oriented strategies are not appropriate in major neurocognitive disorder [18]. The evidence base for sensory, emotional, and environmental interventions demonstrates a need for continued study and more high-level research studies in advanced dementia [18, 20, 24]. However, evidence does support that the presence of a trained caregiver providing individualized interventions does show an immediate reduction in symptoms. Short-term benefits provide relief for caregivers and provide the ability to connect with the patient in the moment. In a systematic review of nonpharmacological intervention, person-centered interventions showed significant reduction in difficult behaviors [24].

Table 5.2 Classification of behavioral interventions

Intervention category	**Examples**
Emotion	Validation of emotions; sharing memories
Cognitive	Cognitive-behavioral adaptations; reward system; time-outs
Sensory	Music, light, warm blankets, pet therapy
Environmental	Simplifying environment; Caregiver education

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Emotional and Cognitive Interventions

Emotional interventions designed to decrease neuropsychiatric symptoms include validation, simulated presence, and reminiscence. Validation is speaking to the emotion, and not responding to the literal translation of communication. Use of validation of emotions in communication showed benefits in mild to moderate dementia but showed no benefits in severe dementia [18]. Simulated presence is the use of recorded voice or videos of a loved one to calm a person with dementia. Simulated presence has limited proven results including no significant difference in response between known and unknown presence and no lasting results in patients with severe dementia [18]. Reminiscence is commonly used to increase interaction and distract from negative feeling. It often involves helping to recall and share long-term memories. Livingston et al.'s [20] systematic review of nonpharmacological treatments reports elevation of mood during the reminiscence, but no long-term behavioral improvement. Because no evidence was found for cognitive interventions in severe dementia, these strategies will not be included in the proposed caregiver guide.

Sensory Interventions

Sensory interventions used to decrease neuropsychiatric symptoms included multisensory interventions, music, touch, movement, aromatherapy, and light. Kverno et al.'s [18] systematic review found four randomized controlled studies in severe dementia and sensory interventions. Evidence shows moderate results in reducing agitation and apathy when aromatherapy is utilized in a diffuser in common areas [18]. Hammar et al.'s [15] study of ten patients with dementia showed decreased negative behaviors, especially with care, when caregivers sang during activities of daily living. Such evidence appears to support that caregiver presence may be a strong factor in success of interventions. Multisensory interventions have been developed to meet hypothesized unmet sensory needs in advanced dementia, especially in institutionalized environments. In a study of eight sessions using multisensory interventions, no increased benefit was found over structured activity [3]. Robichaud, Herbert, and Derosiers [27] found no improvement in behaviors of 40 people with dementia when sensory integration treatments were provided. Music and touch demonstrate decreased difficult behaviors during intervention but with no long-term effects [20, 26]. However, all these studies focused on long-term effects, not immediate reduction in behaviors. Because dementia is a progressive illness, long-term decrease in behavioral symptoms based on an isolated intervention is an impossible goal. However, short-term effects can be replicated when a caregiver is educated on appropriate interventions. Person-centered techniques are more efficacious than isolated interventions. For example, exercise and movement have proven benefit. Evidence supports improved strength and mobility, but not a long-term decrease in wandering or difficult behaviors [24]. However, in a study of 65 nursing home patients with severe dementia, Tappen, Roach, Applegate, and Stowell [30] found a significant decrease in agitation when walking and social conversation were combined. It was also found that 90% of agitated patients were able to complete a walking program when engaged in conversation. Evidence supports individualized interventions and combined use of multiple therapies when working with people with advanced dementia. Table 5.3 details common sensory interventions for behavioral challenges seen in people with major neurocognitive disorder.

Environmental Adaptions

Environmental interventions designed to decrease neuropsychiatric symptoms include modifying physical space, caregiver training, and adjusting activity demand. In 2011, Bédard, Landreville, Voyer, Verreault, and Vézina studied the effectiveness of addressing basic needs to decrease verbal agita-

Table 5.3 Sensory interventions

Intervention	**Condition**
Weighted item (vest, blanket)	Anxiety and apathy
Exercise	Agitation/aggression, depression, restlessness, and anxiety
Quiet space, low stim room	Aggression and anxiety
Baby doll, stuffed animal	Depression, anxiety, motor restlessness
Human touch – caregiver hand holding, massage, personal care (nails, lotion)	Depression, apathy, anxiety
Natural light and outdoor activity	Sleep changes, aggression, anxiety, and depression

tion and found a 50% reduction in verbal aggression when social and physical needs of the patient were addressed. Social and physical needs included comfort and interactions with other people. Meeting the needs of patients with advanced dementia can be difficult due to limited ability to identify and communicate needs. Patients with advanced dementia are reliant on their caregivers to assess basic needs, and therefore results of interventions vary based on accuracy of assessment [28]. Visual changes to space included use of mirrors, sign posting, and using visually complex environments. All had limited long-term reduction in agitation and restlessness [20]. Environmental adaptions need to take into consideration patients' basic need for comfort, and individualized approaches show modest efficacy with advanced dementia [26]. Such studies support that it may be the presence of the caregiver and focused interventions that truly reduce behavioral disturbance in dementia. For example, Doody et al. [10] report grading tasks, toileting schedules, and cues to complete self-care as a best practice approach for dementia, all of which are individualized treatment interventions. Kverno et al. [18] concluded that the most effective recommendations

Table 5.4 Environmental interventions [5, 13]

Intervention	Condition
Circular pathways	Anxiety, restlessness, and agitation
Pained walls/hidden exits	Agitation, restlessness, and anxiety
Caregiver training	Aggression and anxiety
Sleep hygiene (daily exercise, night routine)	Depression, agitation, anxiety, restlessness
Meaningful activities graded to abilities	Sundowning, aggression, anxiety, and depression, apathy and anxiety

were individualized schedules that assist with overarousal and under arousal states and environmental adaptations. Multisensory therapies, social contact, and environmental adaptions had limited effect, but they were limited in consistency of duration and intensity of intervention [24]. Spijker et al. [29] recommend consistent caregiver intervention with high ability and intensity to delay institutionalism. Caregiver training is proven to be the most recommended approach to provide care for people with dementia [7, 18, 24].

In summary, although nonpharmacological interventions in advanced dementia have limited data to support long-term effects of interventions, thoughtful and educated caregivers can provide individualized care plans that can reduce behavior disturbance and increase quality of life [16, 21]. The focused attention of a consistent caregiver may be the best intervention. Providing a caregiver education and meaningful activities is included in the category of environmental interventions. The broad scope of environmental interventions is seen in Table 5.4.

Pain and Quality of Life in Advanced Dementia

Pain is underrecognized and undertreated in dementia [17]. Pieper et al. [25] report that 50% of all nursing home residents with dementia have pain and 80% have behaviors that are difficult for a caregiver to manage. To effectively treat pain, nonverbal signs of pain must be recognized and objectively assessed by a caregiver. Standardized objective measures such as the PAINAD are recommended to decrease pain [25]. Training caregivers in the assessment of nonverbal signs of pain is essential to quality of life of a person with dementia and the successful use of interventions to decrease neuropsychiatric symptoms. In a study of 352 nursing home residents with moderate to severe dementia, assessment and systematic treatment of pain decreased agitation by 20% [16]. Reliable observations of pain behavior require time and consistent report [28]. The caregiver guide will outline strategies to recognize and objectively measure pain.

As the disease progresses, quality of life is a significant issue in advanced dementia. Patients eligible for hospice continue to exhibit pain-related behavior and neuropsychiatric symptoms. Due to the severity of behaviors, many patients do not receive quality end-of-life care. In a study of 123 hospice eligible patients with advanced dementia, over 80% demonstrated significant behavioral challenges including sleep disturbance and aggression, yet few had nonpharmacological interventions provided [19]. Because nonpharmacological interventions have limited long-term effects without consistent approach, in-home caregiver training with tailored activity modification showed to be the most effective intervention for increasing quality of life in people with dementia [7]. The need for consistent caregiving to assess pain and increase quality of life supports the need for a specific caregiver guide for moderate to severe dementia. Pain must be considered when assessing a person with dementia who is exhibiting behavioral challenges. As seen in Table 5.5, nonpharmacological treatments for pain can vary from positioning to gentle massage.

In choosing a behavioral intervention, Fig. 5.1, person-centered plan of care, describes an evolving process. For patient-centered care, interventions of all types need to be based on an individualized assessment of strengths, unmet needs, and previous life preferences. A thorough review of

Table 5.5 Nonpharmacological interventions for pain

Intervention	Examples
Positioning	Bed and wheelchair Evaluate ability to self-propel Evaluate cushion Evaluate height of backrest Ergonomic evaluation by occupational therapy
Touch and massage	Evaluate and treat high or low muscle tone Regular one-step exercise Stretch Heat
Caregiver training	Pain assessment (verbal and nonverbal)
Sleep hygiene (daily exercise, night routine)	Positioning, daily exercise, nighttime routine, natural light during the day, nutrition, and toileting before bed
Meaningful activities graded to abilities	Activities that engage a person cognitively, emotionally, and physically

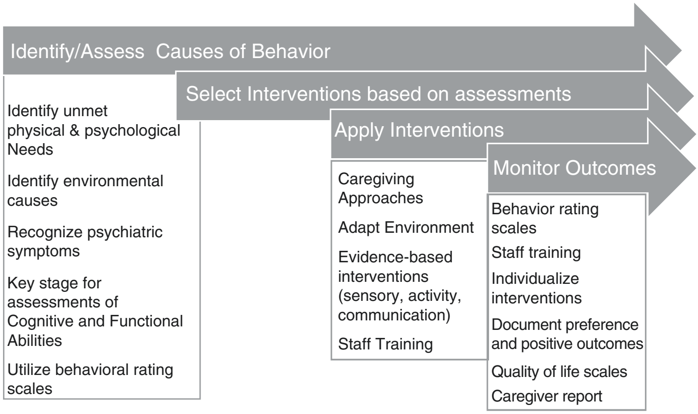

Figure 5.1 Person-centered plan of care. (Also featured in Activities of Daily Living Chapter. Created for this text by Foidel, 2018) [14]

meaningful lifetime occupations and sources of joy needs to be utilized. In addition, individual sensory preferences need to be honored and recorded in a care plan. For example, people have individual reactions to music, massage, and animal-assisted therapy. Information should be gathered through a functional assessment, sensory exploration, and interview of family and previous caregivers. Modifying a person's environment to allow for continued habits and routines can maximize independence and fully utilize strengths of a person with dementia.

Case Study: Gregory

Gregory is a 65-year-old man with advanced Alzheimer's dementia. He has a history of working as a mechanic in a rural area and was a boxer in his youth. He is a lifelong bachelor. He is extremely combative with showers and often refuses to change his clothes. He crosses his arms and stands in the entryway – following guests and going toward doors in his memory care unit.

Evaluation of Sensory Preferences

- Enjoys "hard work" stacking, moving objects, and repetitive exercise
- Irritated with loud noises (loud visitors, shift change)
- Enjoys country music
- Low back pain noted; does not like to sit for greater than 10 minutes
- Wakes up very early (3 am) and likes to go to bed early – sleeps well when busy during the day

Evaluation of Abilities and Challenges [11]

- Can complete 1–2 step tasks
- Able to complete familiar ADLs when cued to initiate
- Limited language skills; aphasia makes speech vague
- Independently ambulatory
- Strength and ROM within normal limits

Intervention Ideas Based on Personal Preferences

- Allow Gregory to be awake early and work on a 1–2-step exercise such as stacking boxes, mopping floor, or moving baskets full of laundry (hard work early in the am mimics life as a farmer).
- Shower in the late afternoon. Place all supplies needed in bathroom and start warm shower. Cue to initiate and then just observe for safety. Recommend female caregivers (habits and routines).
- Regular exercise and ability to walk during the day (maintain sleep at night and help with pain).
- Consider headphones with country music to decrease irritation with noises happening in care facility.
- Keep routine simple. Allow patient safe choices. Avoid shift change.

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Chapter 6

Pain in Older Adults with Neuropsychiatric Symptoms

Susan S. Rose

Introduction

Patsy, a 64-year-old female, walks the halls screaming. Patsy has advanced neurocognitive disorder due to early-onset Alzheimer's disease. She was admitted to the emergency department (ED) after assaulting her husband. During her brief tenure in the ED, she assaulted two nursing assistants and bit a security guard. Patsy has been admitted to the geriatric psychiatry hospital for stabilization.

The interdisciplinary team meets to develop a treatment plan for Patsy. The geriatric psychiatrist verifies the diagnosis of early-onset Alzheimer's dementia (EOAD) and updates Patsy's history to include osteoarthritis and diastolic heart failure. The nursing staff describe Patsy as emotionally labile, with a poor attention span, frowning expression, and poor self-care. The wound specialist reports that Patsy has edema of her feet, with cracked bleeding skin. The chaplain mentions that Patsy frequently talks to herself, often stating "He beat me up." The occupational therapist has evaluated Patsy and reports poor memory, limited insight, decreased executive functioning, and decreased expressive language skills. The physical therapist reports that Patsy is at a high risk of falling. The recre-

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ational therapist mentions that Patsy used to enjoy needlepoint but stopped when it became too painful. The social worker reports that Patsy has been evicted from several long-term care facilities due to agitated and aggressive behaviors. Patsy's husband expresses a concern that she will outlive their finances. He also mentions that Patsy "never complains about pain, even when she worked long hours as a housekeeper."

The team suspects that Patsy's behaviors are communicating pain and distress. Patsy's prior experience of persistent pain may be contributing to under-recognition of pain, consistent with the literature that supports older adults' perception of pain as inevitable. They suspect that Patsy's baseline pain from her osteoarthritis has increased in the context of recent physical aggression with the staff, as well as the influence of her edema and skin breakdown.

Over 100 million Americans suffer from acute or chronic pain every year [1]. The prevalence of persistent pain increases with age, and the majority of older adults have untreated significant pain problems [22]. Statistics on the prevalence of pain among older adults vary considerably, ranging from 25% to 80%. Prevalence of chronic pain after traumatic injury may be as high as 62% [31], and it is estimated that 45% to 80% of individuals residing in nursing homes experience persistent pain [5]. By some estimates, more than 60% of persons aged 75 years and older are afflicted with persistent pain. In individuals with major neurocognitive disorders (NCDs) or dementia, severe pain is chronically undertreated [34].

The most widely used definition of pain comes from the International Association for the Study of Pain, who describe it as an unpleasant sensory *and* emotional experience that is associated with actual or potential tissue damage [12]. However, Kaasalainen [21] offers a useful operational definition of pain that can be applied to the individual with neurocognitive deficits: "Pain is an unpleasant, subjective experience that can be communicated to others either through self-report when possible or through a set of pain-related behaviours (p 7)." As with other chapters in this book, we will focus on those behaviors, as they provide insight into the neuropsychiatric suffering of individuals with neurocognitive deficits.

The terms persistent pain and chronic pain are often used interchangeably in medical literature. The American Geriatrics Society (AGS) endorses *persistent pain* as the preferred terminology, as it is not associated with the negative attitudes and stereotypes often linked to the chronic pain label. The authors also endorse the term persistent pain in this textbook.

Barriers to Effective Pain Management

Before embarking on a discussion of barriers to effective pain management, one must first decide why barriers exist. Barriers can be stratified into layers of provider-centric and system-focused, patient, financial, and ethnicity-centric.

There are several barriers to adequate pain management that can be attributed to the healthcare provider, such as inadequate assessment of pain or pain relief, inadequate knowledge and training in pain management, lack of accountability for pain control, and timidity in prescribing Klerman's salient [23] article aptly described prescribers along a continuum, from psychotropic hedonism (if it feels good, prescribe it) to pharmacologic Calvinism (restricted and repressive opioid-phobic). Placing that continuum in the context of caring for individuals with neurocognitive deficits, the intricacies of assessment and treatment add another layer of complexity.

Systemic and regulatory barriers include federal and state regulations governing the use and abuse of opioids, as well as organizational guidelines from a plethora of legal and regulatory agencies. The fear of regulatory scrutiny and sanctions casts a shadow on prescribers of controlled substances.

Reduced access to specialist or pain management facilities provides additional barriers.

Financial barriers include the obvious barriers of lack of insurance and cost of medications but also include poorly explained reimbursement decisions that add another layer of complexity to care. For example, despite the numerous warnings and diligence surrounding the use of opioids in elders, it remains significantly cheaper to prescribe an oral narcotic than a topical analgesic. Further, some medications are cheaper in higher doses, and using a lower and safer dose may be cost-prohibitive.

Patient-associated barriers may include a reluctance to report pain; a belief that one can “see the pain through”; underestimation of the level of pain; unwillingness to accept pills or injections; fear of addiction, tolerance, or side effects; or poor clinician/patient communication. A prevailing belief that pain is an inevitable part of life can also be contributory; in fact, it is not uncommon for pain to serve as a metaphor for death in older adults who fear that pain indicates a serious illness or poor diagnosis. Barriers to effective pain control are portrayed in Table 6.1.

Adding to the complexity are cognitive deficits, the severity of which contributes to a wide range of problems. Individuals with mild NCDs may have difficulty understanding an intricate pain management regimen. Individuals with major NCD may have difficulty describing or even recognizing pain. Commonly, psychomotor agitation may

TABLE 6.1 Barriers to effective pain control

Physical	Hearing loss precludes hearing instructions about how to ask for or use the medication Visual impairment; reading the bottle Difficulty opening the bottle
Cultural	Some pharmacies are unable to label a bottle in the patient’s preferred language; some prescriptions can only be filled in English
Cognitive	Difficulty understanding a complex tapering regimen Difficulty understanding how to use a pain pump

be the sole observable evidence of pain in an individual with cognitive impairment.

Sensory impairments may preclude an individual from seeing well enough to read directions on the bottle, not to mention getting the bottle open. Egan & Cornally [7] discuss the extent to which sensory deficits, such as hearing loss, interfere with pain management in older adults. Possible issues include not hearing and understanding how to use a PCA pump, or not hearing explanations on how to ask for pain medication, or misunderstanding questions about the nature and extent of pain.

Generational differences add an additional layer of complexity, as discussed in Table 6.2 below.

Of all the barriers, ethnic and racial disparities are the most disheartening. A 1997 study published in *Annals of Internal Medicine* found that 65% of minority patients did not receive guideline-recommended analgesic prescriptions compared with 50% of nonminority patients. These disparities continue to exist. A 2002 study among patients with isolated long bone fractures found that individuals of Hispanic descent were twice as likely to receive no analgesics as those of non-Hispanic descent and African-American individuals

Table 6.2 Generational differences toward pain

Generation	**Attitude toward seeking medical assistance for pain control**	**Tendencies around self-medicating or prevalence of drug use**	**Pain-reporting behavior**
Traditionalists	High trust of doctors Follow orders specifically	Trust OTC Alcohol use	Low "Just how being old feels"
Baby boomers	Autonomy; do own research, trust WebMD	Trust complementary and alternative medicine	High Aversion to tolerating pain

were found to be less likely to receive emergency department analgesia than Caucasian individuals. A 2017 analysis of physician patterns of analgesic prescribing for patients with noncancerous chronic pain found that Hispanic patients were less likely to be prescribed opioids [24].

Harrison, Lagisetty, and Sites et al. [14] found that the greatest increase of opioid use over the past several years has been among non-Hispanic White individuals, after adjusting for age and gender.

These disparities are even more egregious when viewed against intercultural differences in cell metabolism. Exploration of membrane-associated proteins located in the mitochondria or endoplasmic reticulum of cells highlights ethnodisparities in cytochrome oxidation. For example, ethnic differences have been identified in studies demonstrating that Asians and African Americans metabolize opoids differently than Caucasians, yet these differences are rarely discussed [17].

Physiology

Patsy was started on scheduled acetaminophen, since her cognitive deficits interfered with her ability to ask for pain medication. Low-dose oxycodone was prescribed on an as-needed basis. The nursing staff used a behavioral scale for assessing pain, instead of using a verbal questionnaire for Patsy.

The pain threshold increases with aging. A meta-analysis of 50+ studies indicated a definite evidence of an increase in pain threshold with advancing age [13]. Compared with younger adults, persistent pain appears to be more common, and of longer duration, in those older than 65 years. In fact, almost 60% of older adults have pain that persists for 1 year or more, compared to 37% of young adults.

Pain also has less psychosocial impact, compared to younger adults. Older adults with chronic pain experience better mental health than younger counterparts, including less avoidance of fear, and tend to be less passive with coping skills and exhibit more control over life events. The good news is that older individuals tend to cope better with pain. The bad news, however, is that older individuals tend to cope by decreasing function and accepting pain as a consequence of aging. This stoicism and acceptance of pain as inevitable leads to a vicious cycle of needless suffering [35].

Physiological Considerations

The prevalence of chronic medical conditions increases with age. Eighty-two percent of older adults have at least one chronic health condition; and 65% have more than one. Seventy-two percent of older adults have musculoskeletal disorders that are most often associated with persistent pain, including osteoarthritis, ankylosing spondylitis, and rheumatoid arthritis [26].

The most significant pharmacokinetic effect in aging has to do with reduction in renal clearance. Kidneys decrease in size, as well as function, throughout the lifespan. The decline in renal function begins after the age of 40 at a rate of approximately 1% per year, or a 1 mL/min per year decline in creatinine clearance. By the time an individual celebrates their 80th birthday, their blood flow to the kidneys is only 40–50% of those individuals celebrating their 50th.

The second most significant effect is on the brain. Brain volume decreases, both in size and weight. Generally speaking, older adults have increased sensitivity to centrally acting drugs such as benzodiazepines and opioids. The adrenergic and cholinergic autonomic nervous systems, however, generally have decreased sensitivity to receptor-specific drugs such as beta-blockers.

Liver function also slows down as we age; in fact, most estimates pace liver function at almost 50% of normal function after age 65. An aging liver is associated with prolonged drug clearance due to decreased first-pass and blood extraction, which is due to lower gastrointestinal absorption or decreased portal and arterial blood flow. Hepatic phase I reactions involving oxidation, hydrolysis, and reduction appear to be more altered by age than phase II conjugation such as acetylation, glucuronidation, sulfation, and glycine conjugation. Unfortunately, liver function tests (LFTs) are often normal despite these changes in the elderly liver [22].

Elderly patients present with increased fat mass, decreased muscle mass, and decreased body water, which have important ramifications on drug distribution. Lipophilic medications such as fentanyl and lidocaine may have an increased duration of effect as more of these medications are absorbed by fat mass and will have an increased volume of distribution. Water-soluble drugs are less efficiently distributed and result in higher plasma concentrations at equivalent doses and therefore result in a higher frequency of side effects.

Patsy's initial pain regimen was ineffective, and she exhibited functional decline. She refused to leave her bed, her feet became swollen, and her verbalizations became more inconsolable.

Clinical Pearl

Decreased liver and kidney clearance cause an increase in drug half-life for analgesics that undergo significant first-pass metabolism. These drugs, such as lidocaine and opioids, should be initiated slowly and at lower doses to avoid complications. Benzodiazepines and tricyclic antidepressants will also have greater likelihood of side effects.

Undertreated Pain

Pain is disproportionately undertreated in individuals with severe neurocognitive deficits due to the difficulty assessing symptoms of pain. The behavioral impact of undertreated pain is significant. Common neuropsychiatric symptoms of pain include physical agitation or aggression. Combativeness is commonly experienced during episodes of personal care, such as bathing or toileting. Protective posturing ranges from withdrawal into a fetal position to taking a threatening boxer's stance. Grimacing may be subtle or accompanied by distraught vocalizations that can range from repeatedly calling out or perseverative phrasing to crying and screaming.

Undertreatment of pain may be due, in part, to the use of subjective evaluations of pain rather than validated clinical scales [2]. Individuals with NCD are often impaired in their ability to provide reliable subjective pain ratings [28], particularly as the disease progresses, and they report pain less frequently and at a lower intensity in clinical settings than healthy seniors [3]. Regular pain assessment has not always correlated pain score or with analgesic use [34].

The sequelae of undertreated pain is concerning. Excessive pain decreases functional status, which begets deconditioning, which begets death. Undertreated pain leads to iatrogenic events, such as inhibited respiratory effort, pneumonia, deep vein thrombosis, and other perils of immobility.

Management of pain is crucial, as undertreated pain is a precipitating factor for delirium. While postoperative pain may be a more recognizable condition, pain can occur from a variety of sources. Fundamentally, one of the most common sources of pain in hospitalized older adults is musculoskeletal pain related to immobility. Complicating things further, many clinicians incorrectly assume opioids are the cause of delirium in patients with pain, leading to a reduction in dosage or discontinuation of pain medications altogether. In fact, undertreated pain may be a stronger risk factor for delirium than pain medications [32]. Pain management regimens that involve scheduled analgesia are associated with lower incidence of delirium.

One of the more circuitous pathways in which pain contributes to delirium has to do with inappropriate and continued secretion and/or action of antidiuretic hormone (ADH). Undertreated pain contributes to the syndrome of inappropriate antidiuretic hormone secretion (SIADH), which in turn contributes to hyponatremia, which in turn contributes to delirium. In older adults, even the mildest dip in sodium can result in delirium. Hyponatremia-related deliriums also have a fairly pronounced anxiety component. Additionally, hyponatremia-related deliriums tend to take a long time to resolve, and symptoms often persist long after the sodium normalizes. Therefore, thorough and vigilant monitoring for pain can go a long way toward reduction of delirium risk factors [33].

Assessment

The PAINAD was used to assess Patsy's symptoms.
PAINAD Score:

- *Breathing: Patsy's breathing is normal. Scored as 0.*
- *Negative vocalization: Patsy repeatedly calls out; her tone is distressed, and volume frequently escalates to screaming. Scored as 2.*
- *Facial expression: Patsy frequently grimaces and looks troubled. Scored as 2.*
- *Body language: Patsy has distressed pacing. Initially scored as 1 and then increased to 2 as she started to become physically aggressive with care.*
- *Consolability: Patsy is frequently inconsolable. Scored as 2.*
- *Score: PAINAD score is 8, indicating severe pain.*

Clinical manifestations of persistent pain are often complex and multifactorial in the older population and may be difficult to assess. Subjective reports are not always accurate. Pain may be underreported due to an incorrect belief that pain is a normal process of aging. Cancer pain tends to be underreported because of fear of disease progression [8]. Autonomy and independence are also factors: it is not uncommon for individuals to deny pain if there is a concern that they may be placed in a higher level of care such as a nursing facility.

Assessing pain in individuals living with neurocognitive disorders can be particularly challenging. A label of dementia may bias the interpretation of pain cues of patients with dementia. Nygaard [27] found that cognitively intact nursing home residents were more likely to receive unscheduled pain medication (33%), compared with cognitively impaired residents (27%), and those with a diagnosis of dementia (12%). Similarly, a 2008 study of 551 pts. in long-term care (LTC) found that reports of pain decreased as cognitive abilities declined. While 80% of residents who were cognitively intact received pain medications, only 56% of those with severe impairments were medicated [29]. Even though the diagnoses likely to cause pain were similar among all residents, those with severe cognitive impairments had fewer orders for scheduled pain medications.

There are numerous rating scales that can be used to assess pain. The most common numeric rating scale (NRS) simply rates pain on a scale from 0 to 10. While this may be the most popular tool, it does not provide a comprehensive evaluation of pain [15].

Verbal descriptor scales (VDS) ask the individual to describe pain from "no pain" to "pain as bad as it could be." Although VDS can have fairly robust reliability, they are influenced by language deficits and limitations in abstract thinking. Pain may be manifested in multiple ways, so a variety of terms should be used to screen for symptoms in older patients, such as burning, aching, soreness, tightness, discomfort, sharp, dull, and throbbing.

The Faces Pain Scale-Revised (FPS-R) (source) was developed as tool for nonverbal individuals; however it can be misinterpreted [20].

The Pain Assessment in Advanced Dementia (PAINAD) scale has been designed to assess pain in this population by looking at five specific indicators: breathing, vocalization, facial expression, body language, and consolability [18, 37]. Reliability of the PAINAD has been reviewed favorably [6, 16], although a panel review of studies examining individual items within the PAINAD identified two variables with unfavorable results. For example, the construct of breathing had low internal consistency [38] and construct validity [36]. Additionally, consolability has not been universally accepted as a robust indicator of pain; the construct may reflect an intervention, rather than a measure of pain, and may be biased due to perceptions of vulnerability [3].

Instead, a behavioral approach to assessment of pain is recommended. Pain behaviors are increased in individuals with NCD due to AD, regardless of severity [3]. For example, crying out is commonly associated with pain, and repeated monosyllabic verbalizations are strongly associated with undertreated pain. Behavioral challenges, such as resistance and fighting with care, are common ways in which individuals communicate pain.

Pasero [25] describes the utility of using (1) nonverbal facial expressions, such as grimacing, frowning, and clenching teeth, in combination with (2) verbal expressions such as moaning, crying, yelling, screaming, or being unusually quiet. Pasero's third factor includes an assessment of body posturing variables, such as guarding, a stiff, rigid, or withdrawing body posture when moving, or extreme postural poses such as having legs or arms drawn up in a fetal-type position.

The team decided to treat Patsy's pain more aggressively. Oxycodone was switched to a fentanyl patch. Stool softeners were used to prevent constipation. Soothing lotions were applied to her feet.

Once Patsy's pain was partially treated, she became less resistant to care. Once her pain was adequately treated, her vocalizations improved, and she no longer paced around the unit. She was able to participate in some social activities, and her affect and demeanor improved.

Treatment

Pharmacological Interventions

One of the most salient pharmacological interventions is the use of plain old acetaminophen. The American Geriatric Society recommends acetaminophen for consideration of initial and ongoing pharmacotherapy in the treatment of persistent pain, particularly musculoskeletal pain, owing to its demonstrated effectiveness and good safety profile [19]. Acetaminophen is contraindicated in individuals with liver failure and should be used with caution in individuals with hepatic insufficiency or chronic alcohol abuse. The maximum daily recommended dose is 4grams in a 24-hour period. That upper limit is reduced to 3 grams for frail elders and further reduced from 50% to 75% in patients with active or recent alcohol abuse.

Nonsteroidal anti-inflammatory drugs (NSAIDs) are among the most commonly used pain medications but should be used cautiously in the geriatric setting. Among older adults hospitalized for adverse drug reactions, nearly one-quarter (23.5%) were attributed to NSAID use [10]. Older adults have a 3-fold risk of gastrointestinal complications with NSAIDs than younger adults [30], and the risk of hemorrhagic peptic ulcer disease jumps almost 13-fold when NSAIDs are used with the common anticoagulant warfarin [9].

Cyclooxygenase-2 (COX-2) selective inhibitors were introduced with the hope of reducing GI toxicity. While their use has been associated with fewer significant GI adverse events, the protection incurred is not complete. In addition, the other types of NSAID-related toxicities are the same. Celecoxib is currently the only COX-2 inhibitor remaining on the market, as both rofecoxib and valdecoxib were withdrawn due to concerns about unacceptable risks of adverse cardiovascular events.

The American Geriatric Society (AGS) guidelines specify that both NSAIDs and COX-2 inhibitors may be considered on rare occasions and used with extreme caution in highly selected patients. That said, a proton pump inhibitor (PPI) or misoprostol for gastrointestinal protection should be used concurrently with nonselective NSAIDs. Individuals taking a COX-2 selective inhibitor concurrently with aspirin should also use a proton pump inhibitor or misoprostol. AGS guidelines also recommend that clinicians should routinely monitor all patients taking NSAIDs for gastrointestinal and renal toxicity, hypertension, heart failure, and other drug–drug and drug–disease interactions [19].

Long-term use of opioids for persistent pain may be associated with fewer potential life-threatening risks compared with long-term NSAID use. That said, opioids have their own set of potential risks, including constipation, nausea and vomiting, sedation, impaired cognition and psychomotor function, and respiratory depression. While most adverse events do decline over time, extended use of opioids may suppress the production of several hypothalamic, pituitary, gonadal, and adrenal hormones.

Methadone is problematic in older adults due to a very long half-life. Newer opioid alternatives include levorphanol, which is similar to methadone, but with less pharmacokinetic and drug interaction pitfalls. Tapentadol is associated with significantly less gastrointestinal distress and constipation. Transdermal buprenorphine is an agonist/antagonist with less risk for the toxicities associated with conventional opioids and with compliance benefits. However, none of these have been extensively studied in frail elders.

Adjunctive analgesics include antidepressants, such as tricyclic antidepressants (TCAs), serotonin-reuptake inhibitors (SSRIs), and mixed serotonin and norepinephrine-reuptake inhibitors (SNRIs). Antidepressants are commonly used as adjunctive analgesics for neuropathic pain and fibromyalgia. For example, duloxetine (SNRI) is FDA-approved for neuropathic pain as well as depression. Tertiary tricyclic antidepressants, such as amitriptyline, imipramine, and doxepin, should be avoided in individuals with NCD because of higher risk for adverse effects such as anticholinergic effects and cognitive impairment [8].

Antiepileptic drugs (AEDs) are commonly used for neuropathic pain. Gabapentin (Neurontin) has FDA approval for postherpetic neuralgia, and pregabalin (Lyrica) is approved for diabetic peripheral neuropathy, postherpetic neuralgia, and fibromyalgia. AEDs can be cognitively blunting and should be used cautiously in older adults with NCDs.

Analgesic effects of steroids can be helpful for a wide range of conditions, such as rheumatoid arthritis, polymyalgia rheumatica, giant cell arteritis, neuropathic pain syndromes, and cancer. Long-term systemic corticosteroids should be reserved for patients with pain-associated inflammatory disorders or metastatic bone pain [8]. Unfortunately, toxicity can be problematic, particularly with long-term use. Clinicians should also be mindful of the risk of steroid-induced psychosis, particularly in individuals at risk of worsening NPS.

Muscle relaxants, which can be useful for relief of skeletal muscle pain, should be used with caution, if at all, in individuals with NCD. Muscle relaxants such as cyclobenzaprine and baclofen are associated with dizziness and increased risk of falls. These medicines are also difficult to stop and must be tapered to avoid seizures and delirium.

Topical preparations have substantial utility in pain management. Topical NSAIDs, such as diclofenac or salicylate derivatives and compounded topicals, have also been introduced as an alternative to traditional oral agents due to their ability to achieve superior tissue levels for appropriately selected inflammatory conditions. For example, diclofenac gel has demonstrated greatly reduced systemic levels compared with oral equivalent doses for the treatment of osteoarthritic pain [4]. Topicals offer better tolerability as well as avoidance of drug interactions, end-organ dysfunction, and gastrointestinal bleeding. Topicals can also provide immediate relief of pain for conditions that affect the dermis, such as shingles and postherpetic neuralgia.

Nonpharmacological Interventions

In a culture in which there is a pill for every ill, it is not uncommon for the use of medication to overshadow other treatment modalities. When offered their choice of a prescription or eight free sessions of psychotherapy, only 7% of depression sufferers in the Sequenced Treatment Alternatives to Relieve Depression (STAR*D) Study chose psychotherapy [11].

Nonpharmacological interventions are vital for pain management in older adults. AGS guidelines recommend that one should never give pain medication without also using a nonpharmacological modality. Combining pharmacologic and nonpharmacologic strategies enhances pain relief. The most frequently used modalities are acetaminophen (61%), regular exercise (58%), prayer (53%), and heat and cold (48%) (cite).

Warm blankets, as well as weighted blankets, can be very helpful, as are other modalities, such as exercise, heat, cold, massage, TENS, assistive devices, or orthotics. An occupational or physical therapy consultation can be extremely helpful.

AGS Guidelines

- Use least invasive route.
- Oral is better than IM.
- Use short-acting analgesia for episodic pain and around-the-clock regimens for continuous pain.
- Long-acting or sustained release for continuous pain only.
- Start low; go slow.
- The most appropriate first choice is acetaminophen.
- For pain uncontrolled with acetaminophen, the use of NSAIDs is appropriate.
- For pain refractory to NSAIDs, a weaker opioid (codeine, hydrocodone, oxycodone) is the appropriate first choice, in combination with acetaminophen.
- For pain refractory to the previous plan, morphine is appropriate. Other pure opioids to consider include hydromorphone, fentanyl, levorphanol, and oxycodone.
- Adjuvant medication may be used to relieve fear and anxiety in the patient as well as for synergism with the previously named medications.

Complementary and Alternative Modalities (CAM)

Forty percent of Americans use complementary therapies (Eisenberg et al.), particularly for conditions such as chronic back pain, osteoarthritic pain, and headaches. Most complementary therapies are used in addition to the appropriate use of analgesics. The benefits of these therapies help to diminish emotional component of pain, strengthen coping abilities, reduce anxiety and provide a sense of control, decrease fatigue, and promote sleep. Ultimately, the use of CAM can enhance comfort and restore hope by returning the locus of control back to the individual.

Relaxation therapies include activities that produce a state of relative freedom from both anxiety and skeletal muscle tension. These can include breathing exercises, imagery, or distraction, in which attention and concentration are directed at stimuli other than pain. Meditation, or focusing one's mind on a single thought, sound, or image in an attempt to promote relaxation and physiologic function, can be helpful. These practices may have limited benefit for individuals with major NCD; however, various modalities can be used with individuals with minor forms of NCDs.

Aromatherapy is commonly used. Lavender, rose, and angelica are reportedly anxiolytic, and clove, cinnamon, sage, eucalyptus, black cumin, and bay leaf reportedly have anti-inflammatory benefits. Black pepper and capsaicin can be used for arthritis pain. Topical clove oil has been used as an analgesic in dentistry for many years.

- Respect the patient's report of pain.
- Be accountable for pain control.
- Advocate for appropriate analgesics to relieve pain.
- Assess pain relief after medicating.
- Listen and provide a caring presence, especially when pain is not immediately alleviated.
- Pain is what the world does to you; suffering is what you do to yourself.
- Reassurance – it is unreasonable to expect life to be pain-free, but I will help you learn how to manage it.

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Chapter 7

Frailty, Resilience, and Palliative Care Considerations for those Living with Dementia

Maureen C. Nash

Dementia as a Chronic Life-Limiting Illness

Dementia is a chronic illness, often lasting for the last one to two decades of a person's life. Most types of dementia are progressive, a condition in which neurons in the brain stop functioning and die over time, leaving neurologically induced cognitive, emotional, and behavioral deficits. This is analogous to congestive heart failure where cardiac cells die or stop functioning and the heart loses the ability to pump blood efficiently. These similarities have led many to conceptualize dementia as a form of chronic brain failure.

One reason for the paradigm shift of viewing dementia as chronic brain failure is to enable better planning over the entire course of illness. However, having a terminal condition is not the primary thing to know about someone living with dementia and need not be the defining fact of a person's life. Understanding the progressive nature of dementia, it is essential to learn a person's habits and preferences as early on as is possible. This

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can then be combined from what is learned through regularly reassessing a person's abilities with objective functional cognition tests. Person-directed care is the ideal. When that is not possible, person-centered care can be led by those who know the person best. In this chapter the history of the movement to transform dementia care to person-centered and person-directed care is reviewed. Next, frailty and resiliency are reviewed in the context of dementia. It is essential to clarify and update the goals of care throughout the course of the illness. To palliate is to focus on decreasing suffering and therefore encouraging use of the palliative care model is reviewed. Dementia as a terminal illness will conclude the chapter.

The "D" Word

There is significant stigma associated with the word dementia. *The D word*, dementia, follows in the footsteps of the *C word*, cancer. In the 1950s and 1960s, people spoke of the C word when referring to cancer. Cancer was considered an automatic death sentence. There were few treatments available, and those available often caused horrifying side effects and functional decline, with a successful treatment rate of less than 33% [1]. In Britain, a debate raged over whether to educate the lay public about cancer at all and the experts, at the time, voted against education. Fear and dread surrounded the topic and even the word. Compared to today, cancer was poorly understood. Previously cancer was seen as a monolithic entity. Only in the past few decades have the etiology, prognosis, and treatment for hundreds of distinct types of cancer been understood [2]. Radiation and surgery were the mainstays of treatment, and survival rates were low. Though radiation and surgery may stop some forms of cancer, their efficacy was marginal in decreasing mortality, and the physical toll of treatment was great, at times inflicting suffering considered worse than the original disease. It was not just controversial to educate the public at large about cancer but even to tell people of their own diagnosis [3]. Gilbertsen and Wangensteen presented a 1961 paper "Should the Doctor Tell the Patient that the Disease is Cancer?" presenting objective data that a large majority of people with cancer wished to be told of the diagnosis. At the time, a debate occurred in medical circles about informing people of what was known about their diseases…cancer came to be known as "the C word." In Britain, the decision was to withhold the diagnosis of cancer from the person [4, 5].

The modern idea of informed consent, explaining the diagnosis, risks and benefits of various treatments in person-centered language, including no treatment, emerged quite slowly in the medical world. A similar revolution in the diagnosis of dementia syndromes is now emerging. Healthcare professionals remain reluctant to give the diagnosis of dementia. In 2015 physicians who diagnosed someone with dementia disclosed this to them less than 50% of the time [6]. This lack of disclosure may partially be explained by the current lack of disease modifying treatments. The history regarding diagnosis and treatment of cancer is reviewed because the same ethical discussions are being repeated and lessons re-learned in the present day about dementia.

The term dementia encompasses multiple syndromes as outlined in earlier chapters. But in the public mind, a single syndrome of dementia exists. This is repeatedly seen in books written for the public, as well as some written for healthcare providers. People dread hearing a diagnosis of dementia for themselves and those they care about. Sometimes the dread is more specific: "It is OK if I have dementia as long as it isn't Alzheimer's." This belies the reality that the vast majority of those with dementia do have Alzheimer's disease or Alzheimer's plus a second type of dementia [7].

Transitioning to Person-Centered and Person-Directed Care

In the 1980s, a movement, sometimes labeled the culture change movement, was started by a few providers, advocates, regulators, and caregivers in nursing homes. This movement emphasized shifting care of persons living with dementia away from an institutional and regulatory focus to an individual person-centered focus. One example of this paradigm shift was simply knowing what time the person likes to get up in the morning and adjusting the care setting's practices and policies to meet the individual's needs and desires. At the time this was a revolutionary concept in most care settings. Many a rocky start to the morning for resistive residents was resolved by allowing people to sleep in and awaken on their own schedule. Organizations that worked to this end include the Pioneer Network, the Eden Alternative, and others. One approach, the *Best Friend*s model outlines the rights those living with dementia have and what elements of a person's life story are important to know [8]. There are many other organizations that now share this same mission. The focus is on a personal and respectful relationship between person and caregiver. This is especially important for paid caregivers. However, even in the case of family or friend caregivers, a thorough review of information about a person's life is recommended especially those segments prior to knowing family or caregivers. Spouses are sometimes surprised to learn childhood details, while siblings and childhood friends at times have less knowledge about a person in their adult life. The premise of the Best Friends model is to treat people living with dementia as one would treat a friend, knowing likes, preferences, and style. Knowing the person's life story is one important tool to assist them in a personal and meaningful way. Moving to the next step in problem solving and care planning is much more easily and individually accomplished when a person's personal and cultural history is understood [8]. It remains important to maintain solid professional boundaries even when using this Best Friends approach toward caregiving of vulnerable older adults because the power differential inherent in a caregiving relationship precludes actual friendship. Those who only hear about the Best Friends approach without understanding the context may be more susceptible to boundary violations.

The Eden Alternative continued to expand the culture change movement. The Eden Alternative philosophy began in 1991 when an emergency department physician found himself as the medical director of a nursing home. He came to view aging and working with those who found their home to be a nursing facility in a whole new light. He determined that the three most serious challenges for those living in nursing homes, including those living with dementia, were not their medical problems or nursing needs but rather, loneliness, helplessness, and boredom [9]. The culture change embodied by the Eden Alternative, the Best Friends approach, and other culture change traditions continues to be reinforced and enlarged by the Pioneer Network and other organizations [10].

There is a new emphasis by some leaders in the medical field to focus on the positive aspects of living with dementia. The rationale for this movement is centered in concerns that respect and dignity for people, including those who have dementia, have been lost and there is a need to focus not on what people cannot do but on those things a person can do. This is called "the positive approach to dementia care." Dr. Power and others postulate that the distress seen in people with dementia is not due to the dementing process itself but instead due to a state of compromised well-being. He and others emphasize person-directed and strength-based care. The movement referred to as a positive approach is contrasted with an approach that focuses on the decline and death that accompany advancing dementia [11]. Some have expressed significant concerns on a shift away from research supporting those with dementia, as they lose functioning, to promote personhood. It is vital to respect people living with dementia and let them direct care whenever possible as well as focus on abilities and support all efforts toward resiliency. It should not prevent a parallel focus on the prognosis of dementia and preparing for the end of life. It is vital to plan with and for the future needs of people while always keeping the person and personhood of those living with dementia at the center [12].

Frailty and Resilience

Frailty is a term that is often used by caregivers to describe older adults who are frequently tired or isolated. Formally, frailty is difficult to define precisely. Frail older adults can be described as those who have increased vulnerability to loss of function and debility while having decreasing ability to resist illness. Definitions of frailty vary; some including psychosocial factors and other definitions generally include weight loss, fatigue, low muscle mass/weakness, slowed physical abilities, and low physical activity [13]. The literature describes frailty as a multisystem decline in which older adults are more vulnerable to falls, fractures, and infections. Typically, the organ systems most impacted by frailty are the immune, skeletal, endocrine, and neurological. Those who are frail are increasingly vulnerable to minor changes to their environment [14] (Table 7.1).

Included in frailty is the idea of a *frail brain*, in which frail older adults are more vulnerable to quickly developing delirium. In a simplified model of the frail brain, although structures may not be detectably altered, the metabolic efficiency of neural networks is decreased. The frail brain has less efficiency or resistance to changes such as introducing new medication, infection, and malnutrition [14]. This model of functional brain decline, even though structurally the brain

Table 7.1 Examples of common symptoms of frailty and associated functional deficits

Symptom of frailty	**Functional outcome**
Decreased muscle mass	Frequent falls
Generalized weakness	Fear of falling; high fall risk
Low grip strength	Decreased participation out of residence
Fatigue	Increased isolation; decreased participation
Malnutrition	Increased fractures, increased fatigue
Decreased immune system	Frequent infections
Decreased mobility	Increased isolation; infections and skin breakdown risk

appears unchanged, may explain why functional medical imaging such as PET scans can aide diagnosis of dementia while CT scans and standard MRIs are of far less assistance [15]. Many clinicians increasingly theorize that functional cognitive impairment and frailty occur hand in hand. Impairment in cognition is a central feature of frailty for many older adults. Dementia, coupled with frailty, is a strong predictor of mortality [16]. Identifying individuals who meet the definition of frailty can assist in planning for their care. Preventive care planning for frail elders may include strengthening programs, nutritional support, frequent social interactions, cognitive stimulation, and referrals to skilled therapy for either maintenance or restorative therapy [17].

Frailty is sometimes juxtaposed against resilience. The medical model focusses on the decline of functioning to define older adults rather than using a focus on person-centered care to increase resiliency in older adults. Older adults, significantly more than younger adults, emphasize positive coping with what functional limitations one has rather than a focus limited to reversing physical declines. Older adults are more likely to recognize that reversing physical declines may or may not be possible. This is the nature of resilience. Resilience is not the lack of frailty but rather coping with it in a positive manner. Other elements of resilience in the social sphere include working to improve or change societal ills including supporting the environment, fighting economic inequality, working toward a sustainable future, fighting sexism and racism, as well as preserving earth's finite resources by living simply. Actively supporting good works in society can be an antidote to succumbing to fatigue and loneliness. Successful living in a resilient manner also includes recognition of death as a part of life-successful aging includes successful dying. One key here is working to preserve personal choice and dignity during the final phases of life. It is hypothesized that this is part of the generalized dread of ending up living in an institution. For those with dementia, maintaining control and choice requires active planning early on in the course of the disease [18, 19].

Successful, resilient aging: coping with decline.

Maintaining dignity through a focus on personal agency, social value and quality of one's life as well as the quality of one's death.

(A compilation of the sentiments expressed by older adults in Mortimer, 2008)

Care Conversations as a Central Organizing Strategy

The medical model in the United States centers around acute care. This does not serve those with significant chronic illness very well. When the focus is on the current crisis, understanding and planning for the whole trajectory of disease is easily lost. When one has cancer, there is a focus on maintaining wellness and quality of life, but no one suggests ignoring the life-threatening aspects of that illness. Because the brain is intimately involved in all our emotions, behaviors, and communication, it is essential that we recognize the suffering involved when parts of the brain are not working. In incorporating components of a wellness model, one still needs to acknowledge the larger realities of the underlying disease. Part of honoring the dignity of the person is recognizing personal suffering. Absolutely every person is worthy of dignity and respect including people with neurodegenerative illness. When the discussion turns to caregiver education, it often centers on supporting functioning or decreasing distress of the person with dementia. However, there is a real deficit around education of prognosis and what the end of life looks like for people as dementia advances.

Increasingly we are encouraging frequent goals of care discussions with those who have dementia in the earliest stages of their illness and updating goals as the disease advances. In this way, healthcare decision-makers will have an accurate understanding of what a person values in life, as well as what type of death is unacceptable to that person. By helping to focus on what a person's goals are in the context of knowledge about disease progression, we are much more likely to achieve a palliative approach and decrease suffering over time [20]. Caringkind is an organization in New York City dedicated to education and support for those with Alzheimer's disease and other dementias. After completing a 2012 pilot project around supporting those with dementia as they near the end of life, they developed some guidelines published in a booklet [21]. This is an active area that many organizations are beginning to focus on. There is a strong sense that these goals of care conversations and subsequent palliative care belong in the primary care environment and that those who work in long-term care need to be aware of this information.

When people think about dying, often the model is around cancer where the decline lasts a few months to days or even hours. Figure 7.1 is the common trajectory when one has cancer. Functional capacity is often preserved until near the very end of life.

This is in sharp contrast to the trajectory of functional decline seen in those with major neurocognitive disorder. This has been best researched and described for Alzheimer's disease where the decline is more akin to the example in Fig. 7.2. Drawing this type of diagram during a family meeting can be extremely helpful in explaining where a person in the trajectory of their disease and their life.

Allowing time to discuss the future throughout the illness is important. More than 50% of people in the United States

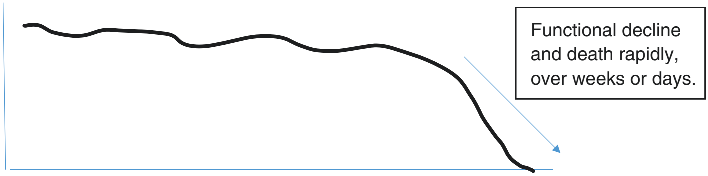


Figure 7.1 Trajectory of life and death with cancer. (Original figure created by Maureen C. Nash, 2017, Copyright Maureen Nash, MD)

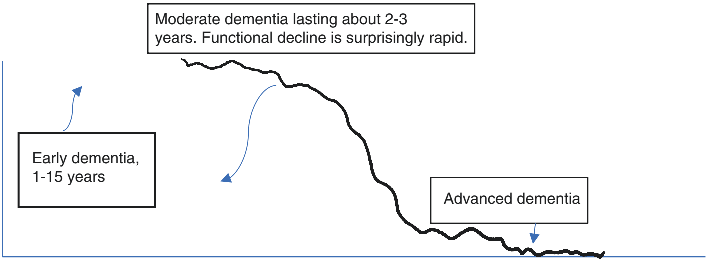


FIGURE 7.2 Trajectory of life and death with Alzheimer's disease. (Original figure created by Maureen C. Nash, 2017, Copyright Maureen Nash, MD)

express a wish to die at home when possible [22]. It is important to remember that the choice isn't about whether death will occur. All living humans die. The choice is about focusing on the quality of life, and the values of the person before the dying process are imminent and while they can discuss their wishes. This is the time to review the link between hospitalizations and permanent functional decline and worsening of cognition experienced by those with dementia [23, 24]. This is a key time to discuss what types of events for which a person would want to be hospitalized, when would they want to consider CPR, and when would they prefer to allow natural death to occur. Generally older adults recognize that life will end and death is not optional. It is often the family of an older adult which finds this concept more challenging to accept. This is one reason it is recommended that family members be included in discussions preparing for the entire course of dementia in addition to the person diagnosed with dementia. Goals of care and what is considered a desirable quality of life are dependent on where along the trajectory of disease one currently is as well as long-standing philosophical and spiritual beliefs.

One common model is to focus on longevity of life prior to the development of a life-limiting disease such as dementia. After the diagnosis, at some point, the focus often shifts to maintaining the highest level of day-to-day functioning that is possible. Once advanced dementia occurs, many choose to focus on comfort and palliation of suffering. If people with dementia are not afforded the opportunity to discuss this early in their illness, their family and healthcare providers may not be able to discuss it with them later in the illness. The content of these discussions needs to be adjusted to the values of the person living with dementia. Also, if the type of major neurocognitive disorder is not Alzheimer's disease, it may have a different trajectory. However, this model of adopting a longitudinal view of the course of disease progression offers those who want to express their wishes the ability to do so [20]. For those with dementia, advanced directive discussions and possibly other documents should address the use of feeding tubes, as well as the use of antibiotics and hospitalization when the goals of care are comfort and the decrease of suffering. There is a significant body of evidence showing that feeding tubes do not prolong life in those with advanced dementia, rather they lead to more invasive medical procedures and infections without a benefit of fewer cases of pneumonia and other negative medical sequelae [25].

The Conversation Project is an online website that has downloadable conversation starter kits at theconversationproject.org

They also have a free course to assist people in having these discussions about end-of-life care. The website also has other resources about advanced care planning.

Palliative Care

This emphasis on early and robust discussion of goals of care is important for those with dementia before the disease advances to the final stages. The time to begin considering palliation or relief of suffering is at the time of diagnosis of any serious illness, including dementia. Whether one is diagnosed with cancer, congestive heart failure, or dementia, it is never too early to look to palliate symptoms. Palliative care involves a focus on relief of suffering and addressing symptoms that impair quality of life. This supports a dignified approach to respecting the personhood of those with dementia while not denying the terminal prognosis that this illness portends. There is concern that the positive approach to the terminal disease of dementia carries a risk of denying the suffering that clearly occurs both in people with dementia and in those who care for them. This does not have to be a binary choice; one can focus on well-being even as one addresses the larger issues around prognosis [12].

Terminal Diagnosis –
what are the person's goals of care?

Aggressive Medical Management/Disease Modifying Treatment	• Options not present • Communication is restricted by a curative only approach to diagnosis
Transition from Disease Modifying to symptom management	• Allows communication about prognosis and care options • Establishes proactive experiences through open awareness • Affords patients and families opportunities to experience end-of-life care preferences • Discussion of advanced directives
Palliative Care: Holistic, symptoms management focused	• Discussion of disease progression, individualized plans of care and advanced directives • Early communication assists in implementation of palliative care • Provide knowledge, characterized by open awareness and focus on quality not quantity of life

Most major neurocognitive disorders are complex progressive neurodegenerative illnesses that lead to a person's death. According to the Alzheimer's Association in 2018 [26], Alzheimer's disease is a top 5 cause of death among older adults. Until recently, there have been few studies in the medical literature about the quality of life and quality of death in people with dementia. Slowly this has been changing over time. In an article published in 2004, Sachs et al. [27] studied how persons with dementia were dying. They found that there was inadequate pain control and many people with dementia were dying with feeding tubes in place despite no benefit to the person who had it. Generally, people did not have the benefits of palliative or hospice care. Over time, in some states those with dementia have moved out of nursing homes and into specialized assisted living facilities or memory care units. A sobering study published in 2014 found that, despite 20 years of education and discussion of the links between pain and dementia, pain was still routinely undetected and misinterpreted in people with dementia [28]. Some positive improvements noted were pain being considered when people were calling out or were grimacing, wincing, moaning, or frowning. There was some mention of pain when staff noted pacing and restlessness. However, screaming and aggression did not lead to consideration of pain. Most pain medications were given as needed even though those with advanced dementia are the least likely to be able to verbally indicate a need, and thus staff must interpret behaviors. There remains resistance to using opiate medications among many staff members because of the concern for safety. Finally, few interventions were described for the common challenge when people with dementia are refusing medications [28].

The National Institutes of Health supported the choices, attitudes, and strategies for care of advanced dementia at the end of life (CASCADE) study in 22 nursing facilities [29]. They found the pattern of symptoms in those with dementia were quite similar to other terminal illnesses such as cancer. This is one of a number of more recent attempts to collect data so that we can shift our outlook and implement appropriate treatment for those with dementia. Results of the CASCADE study, published in 2009, indicated that those with advanced dementia near death suffered significant infections and eating problems. They also found that distressing symptoms likely to cause suffering were common and increased as death approached. Many of those with advanced dementia underwent burdensome interventions that were unlikely to benefit them or improve the quality of life of their lives. Survival was poor after the development of eating problems or infections. One major care variable was how aware the healthcare proxy was of the poor prognosis of the person with dementia. Less than one in five healthcare proxies stated that they had received prognostic information from a physician. Only one in three healthcare proxies reported that a physician had counseled them about likely complications as death neared. Of the residents with dementia who died, three in ten received hospice referrals. Some of the more distressing symptoms experienced during the last few months of life included significant dyspnea, pain, pressure ulcers, aspiration, and agitation [30].

Palliative care is often confused with hospice care. Hospice care involves palliation of symptoms and suffering; thus, it encompasses palliative care. Hospice itself is a defined insurance benefit designed to support people in the final phase of a terminal illness, defined as the last 6 months of life. However, palliative care focusses on prevention and relief of suffering in all settings. It is not limited only to a hospice setting nor only to those in the last few months of life. One of the challenges with hospice care in the past has been that it is modeled on the way terminal cancer progresses. Often when we treat someone with terminal cancer, there is a period of very aggressive medical care, and then once it appears that there will be no further benefit, this care ceases and is rapidly followed by decline and death. Dementia and frailty, on the other hand, are syndromes where over time medical interventions are used less and less because they're effectiveness is noted to be poor. For those with dementia or frailty, it is significantly more difficult to give families and caregivers an exact prognosis. The National Hospice and Palliative Care Organization recommends the Functional Assessment STaging for Alzheimer's/Dementia (FAST) criteria to qualify people with dementia for hospice. FAST scores range from 1 to 7 where those with the lowest scores are the most functional. Typically, a score of 6 or 7 is utilized to qualify for the hospice Medicare benefit.

Stage 7 on the FAST scale

- 7a Person uses less than 6 meaningful words per day
- 7b Person uses one or fewer intelligible word in any average day
- 7c Person has become unable to walk without assistance

One challenge with the FAST scale is that there are many reasons why a person may be unable to walk without assistance that have little to do with their dementia. In 2004, it was found that the FAST criteria generally did not accurately predict 6-month survival for those with dementia. The FAST criteria were not derived from empirical data of people who had dementia. In one study 7 out of 10 people who reached stage 7C in a stepwise fashion by first reaching stage 7A and then 7B did die within the 6-month window expected for hospice qualification. However, for those who reached stage 7C but did not travel through stage 7A and 7B, only three out of ten died within 6 months of enrollment with a median survival of nearly 11 months. In other words, for those who did not progress in a stepwise fashion, 70% of people with dementia live longer than 11 months. For those living in nursing homes, a model has been developed from the minimum data set (MDS). This model looks at ADL dependence, being bedbound, incontinent of bowel, having significant symptoms or illnesses such as cancer, congestive heart failure (CHF), oxygen dependence or dyspnea, medical instability, eating less than one quarter of all meals, sleeping most of the day, being male, and age to greater than 83. A score using this combination of factors was found to predict mortality for those people living with dementia in a nursing home [31].

A group of physicians in a palliative care unit for those with dementia and difficult to control symptoms developed a simpler too to measure suffering in those with end-stage dementia, the Mini Suffering State Examination (MSSE). The Mini Suffering State Exam consists of ten yes or no questions. These questions are designed to correlate with the concept of suffering in those with advanced dementia [32–34].

Criteria found on the Mini Suffering State Exam (Copyright Bechor Zvi Aminoff, Mini Suffering State Examination, 1999, Gerontologie und Geriatrie. Volume: 32, 2. p. 238).

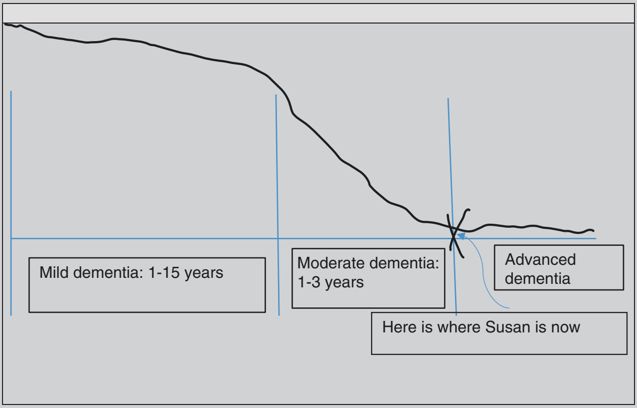
1. Calm? level of calmness of the person with dementia
2. Screaming or calling out?
   Pain especially as evidenced by nonverbal indications?
3. Presence of decubitus ulcers?
4. Malnutrition?
5. Eating disorders as measured by refusals to eat, dysphagia, anorexia or a feeding tube?
6. Need for invasive action such as frequent blood tests, urinary catheterizations, IV or subcutaneous fluids, blood transfusions, dialysis etc.?
7. Acute medical condition such as pneumonia, urosepsis or electrolyte imbalance in the last few months of life?
8. Suffering in the opinion of the medical provider or nursing staff?
9. Suffering in the opinion of the family?

A study published in 2006 found that the MSSE predicts 6 months or less to live when it indicated an elevated level of suffering as evidence by a score of 7–10. The Mini Suffering State Exam is well received by family members and staff. It has been shown in studies to be one of the most usable scales to administer in a clinical setting [35].

Case Study: Susan

Susan had become suspicious that others were stealing from her. This was accompanied by loud yelling and threatening random people who came up to her. She had no past psychiatric history of paranoia or delusions, but these were apparent upon assessment. She developed these same concerns about new people she met, as well as those she recognized. She herself was only oriented to person and could give no accurate recent information. History showed that she had been seen in the ED for a fever and found to have an infected pressure ulcer. She was losing weight and had a very low albumin and total cholesterol. She was using a wheel chair most of the time. She could stand and bear weight but appeared to be apathetic towards walking and did not spontaneously try to get up. Her neuropsychiatric symptoms responded to a combination of environmental support and medications. She was still being treated with warfarin for long-standing atrial fibrillation requiring frequent lab draws especially as her oral intake remained varied. Her family thought she was suffering as did her primary care provider. Her Mini Suffering State Exam score was 7. Because she was still verbally interactive her family was very surprised to hear that she was at high risk of death from the advanced dementia.

Occupational Therapy had seen Susan for an evaluation. Her Allen Cognitive Level was 3.2. This is consistent with severe functional impairment. Someone functioning at this level needs 24-hour supervision, consistent routines are recommended. Communication requires clear and concise statements. Eating, dressing, hygiene, toileting require cueing, assistance and supervision. The drawing below was shared with Susan's family during an office visit.



After this discussion, the family decided to pursue a palliative care pathway. Routine lab draws were stopped, Susan was offered finger foods meeting her past preferences. All medications that were unlikely to add to her quality of life over the next year were stopped. She became slightly less apathetic after 4 cardiac medications were stopped. Approximately 4 months after this assessment, Susan died in her sleep in her daughter's house.

- Physicians and other healthcare professionals should consider palliative care at the time of diagnosis of any serious chronic illness, including dementia.
- Discussions around goals of care need to be honest and open, with periodic updates as life progresses.
- Increasing frailty and promoting resiliency can coexist.
- Education and support are essential for family and all caregivers.

- Treat the person, not the symptom.
- Advanced Dementia is a progressive, terminal illness.
- Quality of life includes engagement in meaningful activity, connection with others including caregivers, and controlled pain.

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Chapter 8
Strength-Based Person-Centered Dementia Care: Activities of Daily Living

Sarah E. Foidel

Completing Activities of Daily Living

This chapter illustrates the interdisciplinary approach to person-centered care during one of the most challenging, yet important, tasks that *daily* for those with advanced dementia: ADL care. Caregivers of people with advanced dementia spend a great deal of the day assisting with basic self-care. The time demand results in exhaustion and elimination of engagement in meaningful activities or social relationships. In America, approximately 15.7 million adult family caregivers care for someone who has dementia (Alzheimer's Association, 2015). The transition from mild neurocognitive disorder to major neurocognitive disorder (dementia) is marked by a decline in function in everyday activities, notably activities of daily living (ADLs). People with moderate to severe dementia lose basic awareness of self-care needs, ability to sequence routine tasks, sense of time for completion, and memory of what self-care has been completed. ADLs are usually defined as feeding/eating, dressing, toileting, hygiene,

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and showering. However, other definitions of ADLs include communication, mobility, and sexual activity.

Combative behavior during provision of activities of daily living is of high concern to direct caregivers. Aggressive behavior during care has been identified as the most distressing neuropsychiatric symptom in caring for people with dementia and often leads to helplessness on the part of the caregiver [7]. In the same study, the most common caregiver response to combative behavior with care was to simply continue with the task [7]. Such findings indicate the need for accessible caregiving strategies to allow for person-centered care. Using the model of person-centered care, challenging behaviors have begun to be described as acting out unmet needs and emotional distress, yet this does not decrease combative behavior without thoughtful, assessment-driven care plans. The authors of this text advocate that this type of acting out be reframed and interpreted as behavioral communication of unmet needs and/or emotional distress. It is essential for a caregiver to interpret what the person living with dementia is communicating with their behavior in order to understand the specific challenge a person faces with ADL, thus allowing for essential task completion, personal dignity, and maximum independence.

Eating and Feeding

To complete self-feeding, one must have the postural and motor control to bring the food from plate to mouth. The second part of the task involves chewing the food and swallowing it. Both eating and feeding can be impacted by dementia. Feeding and eating intricately involve the sensory system, internal sense of hunger, and reflexes.

In the case of major neurocognitive disorder, the brain may change and lose memories of what food is, the drive to eat, and the ability to use tools to eat. In addition, the parts of the brain that interpret sensory information, smell, sight, taste, and texture become altered. Without this information, food may be unappealing or unsatisfactory. The drive to eat, which is housed deep in the brain, will generally last longer than the ability to choose food, prepare ford, or use feeding utensils, which are all functions of our cerebral cortex. Frontal lobe function changes underlie the change in eating behaviors. The involvement of the orbitobasal frontal lobe, temporal pole, and amygdala has been found to be key to the changes in appetite behaviors in advancing dementia [3]. Specific behavior changes include appetite changes, food preference alterations, and change in oral behaviors (grabbing food, oral fixations). These behaviors are more prevalent in both Alzheimer's and frontotemporal lobe dementia [3]. Swallowing difficulties tend to be related to the primary motor tracts and cranial nerves, most commonly found in neurocognitive disorders related to vascular or acquired brain injury. Swallowing difficulties need direct intervention by a physician, nurse practitioner, occupational therapist, and/or speech language pathologist due to aspiration risk. Change in appetite is also included in the Neuropsychiatric Inventory, a common tool to measure behavioral disturbance in dementia. It described weight gain or loss or a change in food preferences [2]. The most frequent causes of decreased intake in people with dementia are thought to be related to decreased appetite, disorientation around meal times, poor food recognition, eating inappropriate nonfood items, difficulty self-feeding from motor abilities, decreased chew or swallow, and forgetting how to use utensils [6]. Overeating is occasionally described, most commonly in those with significant disinhibition and frontotemporal dementia. Degeneration of the hypothalamus and orbitofrontal cortex/reward pathways as well as some hormonal abnormalities has been described in frontotemporal lobe dementia [1]. As seen in Table 8.1, feeding and eating behaviors vary depending on the type of neurocognitive change.

To complicate the dynamics of self-feeding, consuming meals is not only driven by survival but is heavily influenced by routine, emotions, and culture. Families gather at the table for meals, celebrate holidays, utilize food for spiri-

Table 8.1 Typical eating and feeding changes based on neurocognitive changes

Symptom	**Reason**	**Impact**	**Typical conditions**
Sitting at the table and not eating	Apraxia (decreased motor planning) Decreased EF (initiation)	Poor nutrition Weight loss Appearance of apathy or depression	Alzheimer's dementia Vascular dementia Frontotemporal lobe dementia
Eating different foods Decrease in appetite	Change in sensory system Cranial nerve Involvement	Decreased intake Decreased taste, smell	Frontotemporal lobe dementia Traumatic brain injury
Increase in appetite	Hypothalamus Peripheral hormone changes	Appetite stimulation	Frontotemporal lobe dementia
Dropping food/ spilling Decreased posture at table	Tremors Poor fine motor control Cerebellar symptoms	Decreased intake Decreased social participation at meals	Parkinson's dementia Cerebellar CVA Traumatic brain injury Huntingtins Lewy body dementia
Pacing during meals	Poor memory Pain Poor attention	Poor intake Malnutrition	Parkinson's dementia Alzheimer's dementia Delirium
Coughing and decreased ability to swallow	Cranial nerve involvement (V, IX, X, X, XI, XII) Change in tone and muscle strength	Aspiration Pocketing food Poor oral hygiene Malnutrition	Vascular dementia (Post CVA, especially with hemiplegia) Traumatic brain injury

Table 8.1 (continued)

Symptom	**Reason**	**Impact**	**Typical conditions**
Eating spoiled foods Poor hygiene at meals Poor oral hygiene	Poor memory Poor EF Poor insight Cranial nerve involvement Poor taste/smell	Infection Illness Aspiration	Frontotemporal lobe dementia Alzheimer's dementia
Grabbing food from other's plates	Disinhibition	Poor social participation Aggression with peers	Alzheimer's dementia Frontotemporal lobe dementia Huntington's disease
Missing parts of the plate, spilling, difficulty finding food Missing chair when sitting down	Visual Perceptual Deficits Occipital lobe involvement Cranial nerve involvement (II, II, III, IV, VI)	Poor intake Risk of falls Poor social participation	Lewy body dementia Traumatic brain injury Vascular dementia/post CVA

Original Table by Sarah Foidel, 2018

tual celebrations, and often use food to navigate grief. Depending on cultural and social economic background, *food security*, the feeling of food being available, can greatly vary. Individual relationships with food change with dementia. However, understanding individual food preferences and motivations can greatly impact a person-centered care plan. In a 2016 investigative study, serving individualized traditionally and culturally appropriate foods to a person with dementia, some patients who normally could not feed themselves were able to eat independently. Overall, increased joy and socialization were noted by the researchers [5]. Figure 8.1 describes the multifactorial relationship of people with the activity of feeding and eating. Additional

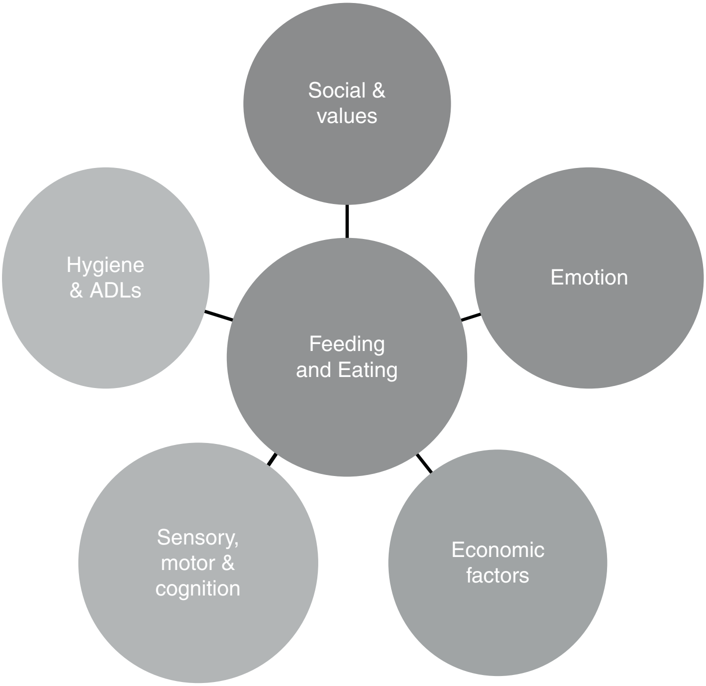

Figure 8.1 Influences to Feeding and Eating. (Created By Sarah Foidel, 2018)

factors include religious preferences, beliefs regarding food value, body image, and social preferences for eating.

Oral Fixations and Appetite Change

Several parts of the brain are key to the reward system involved in appetite. It is generally understood that serotonin is one key neurotransmitter involved in appetite regulation [4]. Because of the neurodegenerative nature of dementia, general abnormalities of neurotransmitters and neurotransmitter receptors can be assumed to be occurring and increasing as brain atrophy increases. In addition, without the frontal

Table 8.2 Oral fixation

Signs of oral fixation
Chewing for prolonged periods
Taking up or increase in smoking
Chewing tobacco
Chewing on nonfood items
Overeating (gorging on food)
Perseverating on one food item (candy, coffee)
Picking at lips and mouth
Eating paper or self-care items
Drinking household products/ hygiene products
Sucking on fingers/ licking fingers
Biting on objects (pencils, toothbrushes)

Original Table by Sarah Foidel, 2018

part of the cerebral cortex to inhibit impulsive behavior, oral fixations (Table 8.2) and changes in appetite may be noted. These symptoms of severe frontal lobe involvement include chewing, impulsive eating, attempting to digest nonedible items, touching the mouth, and gorging. Frequent interventions include safe oral fidgets (objects to chew on), allowing access to safe oral fixation relief (decaffeinated versus caffeinated coffee) and distraction with other sensory input (exercise, weighted blankets).

Tool Use for ADLs: Apraxia

The inability to use objects or tools appropriately is often seen as memory loss, but is usually caused by motor planning impairment. Motor planning, or praxis, is the sequencing of steps it takes to carry out a task. This sequence is housed in procedural memory in the premotor and secondary motor complex. Apraxia is a term used to describe difficulty with carrying out a purposeful task, when it is not due to muscle weakness, sensory loss, or inability follow directions [14]. In major neurocognitive disorder, frontal lobe deterioration can lead to motor planning disruption and is usually assessed by excluding other disorders that may interrupt carrying out a task [14]. A healthy brain understands how to use a familiar tool upon sight and can go through a series of steps automatically and without conscious thought to use the tool appropriately. Multiple types of apraxia exist. *Ideational apraxia* refers to the inability to sequence tasks in order and maintain logical steps and can result in tool misuse [14, 44], while Ideomotor *apraxia* generally refers to the idea that the task is maintained but initiation of the amount of force or length of steps is disrupted [14, 44]. Systems involved include visual and tactile processing, the premotor area of the frontal lobe, and the primary motor area of the brain. Other essential areas of the brain include the cerebellum for timing and error correction as well as the basal ganglia for automatic movements including initiating and inhibiting movements in overlearned tasks or negotiating changes as the task is being accomplished. A first-line intervention for apraxia is task simplification. Apraxia is not only the inability to use tools but often the misuse of tools: the fork is upside down, the knife is used for soup, or food is mixed together on the plate in an unconventional manner. Poor initiation can also be a part of apraxia. If the peron with dementia is unable to pick up the fork, placing it in their hand can initiate motor planning and participation in self-feeding. Guiding through the first step will often initiate the person's motor planning part of the brain and engage procedural memory for task completion. Often simplifying the task of eating (Table 8.3) can assist in decreasing the functional impacts of apraxia. Apraxia can also impair other areas of ADLs including dressing, hygiene, and bathing.

For people with Alzheimer's dementia, social cognition may remain in place until later stages of the disease. This makes diagnosis in the usual PCP office setting more difficult but is a major area of strength when care planning. Because

Table 8.3 Simplification ideas

Consider less food on the plate: 1–2 items at a time
Small portions: more can always be served
Serve food that requires one plate and one utensil
Provide modeling, eating with a person adds natural context
Do not ask questions about the meal – talking can be a distraction
Physically guide to the first step or bite and back off, don't jump into feeding
Consider high-contrast plates (bright colors yellow or red)
Consider finger foods (adult-oriented)
Provide frequent small meals

Original Table by Sarah Foidel, 2018

of this intact social cognition, physical modeling of a familiar task in a natural context may assist with ADL completion. For example, eating with the person living with dementia provides a socially normal behavior example and physical modeling of the task. It is important for the caregiver to remember that as a brain deteriorates, it becomes harder to think about more than one thing at once. Maximize the person's ability to attend by limiting how many sensory systems are being used. Music can be distracting and compete with meal task completion. In addition, asking questions or talking to a person while eating may distract from a meal. This is care planning that recognizes decreased executive function and complex attention function but supports the person living with dementia by maximizing the ability for the preserved simple attention domain to activate.

For a person who is struggling with multistep tasks, using utensils may be limited, and finger foods may become the best most viable option. Finger foods are an option when an adult loses the ability to use utensils effectively. However, finger foods need to be adult appropriate. Unlike young children, adults have developmentally achieved the ability to feed themselves and become frustrated with their inability. If intake has significantly changed, nutrition is always a concern. If weight gain is a health concern, a referral to a dietician or nutritionist can be considered. The majority of people in late-stage dementia lose weight, and any calories are good calories. Avoid food that is messy, has a large amount of sauce, or is difficult to put on a fork or spoon. Avoid simply taking off sauce or removing items from a meal (example just providing plain noodles to avoid mess) as that will make food unfamiliar and unappealing. Finger foods for adults need to be designed in ways that are age appropriate, familiar, and encourage independent intake.

Adaptive equipment can be helpful for those who struggle with self-feeding. Always choose eating utensils that are as familiar as possible. Avoid items that would not be naturally associated with eating (complicated tools, children's cups). For example, a plate with higher edges may assist in self-feeding (scoop plate), or built up handles on utensils and cups may help with grasp or visual perceptual deficits. High-contrast plates can help with low vision. For people with visual perceptual issues including occipital lobe damage that impacts spatial relations or figure ground perception, high-contrast plates are a person-centered way for the person living with dementia to avoid spills and frustration. Always consider non-breakable plates and glasses. Table 8.4 lists common equipment that is helpful. Many of these items can be found in catalogs that specialize in older adults, websites that market dementia care products, or rehabilitation catalogs.

The Restless Eater

People with advanced dementia often exhibit motor restlessness. This can have many causes including anxiety, confusion, pain, or medications. Some strategies for reducing confusion or restlessness involve environmental modifications. Keep the dining area simple. Only provide the tools needed for this meal, and remove clutter from the table. Chairs should be comfortable, and place the person with dementia with a table height that allows their elbows to rest comfortably at the table. Push the person up to the table and have food ready. Limit other distractions, which include social conversation in

Table 8.4 Assistive eating

Scoop plate
Utensils with built up handles (limited grasp)
Nosey cup (nose cut out for those who do not lift their chins)
High-contrast plates
Weighted utensils (increased proprioceptive feedback or decreases tremors)
Swivel head utensils for tremors (intentional and resting)
Nonskid bottoms on plates or nonskid mats
High-contrast plates for low vision

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advanced dementia. Additional strategies include a gently rocking chair, providing finger foods, walking with the person while they eat (cup with straw or finger foods), providing certain types of music during meals, and physical modeling. Shakes and high-calorie nutritious juices can be used for people who are unable to sit still and complete a meal. Leaving finger food snacks and cut up fruit or crackers in a person's room can encourage spontaneous eating. Cups of water can also be left out in activity areas and will often be spontaneously and independently picked up to drink from. Leaving cups next to sinks can encourage drinking after hygiene completion to decrease the risk of dehydration.

Trouble Swallowing

Difficulty swallowing can happen for a number of neurological reasons, and it is important to watch for choking, pocketing of food (food remaining in the mouth especially in the cheek area and not swallowed), and coughing. A person with advanced dementia may also have trouble swallowing from some medications prescribed to help decreased combative or dangerous behaviors than can cause abnormal muscle tone changes. If trouble swallowing is observed, a speech pathologist referral should be completed immediately to recommend food textures

Table 8.5 Referrals to health professionals

Feeding/eating concern	Appropriate referral
Difficulty with swallow, coughing, choking, and cognitive concerns	Speech pathology
Difficulty using utensils, poor posture, poor fine motor control, and cognitive concerns	Occupational therapy
Poor nutrition, poor diet compliance, and weight loss/weight gain	Nutritionist
Difficulty with swallowing prescribed meds, concerns about vitals, and concerns about side-effects of medication	Prescriber: primary care provider, psychiatrist, mental health nurse practitioner, and geriatrician

and thickness of liquids to decrease chance of aspiration. In general, the thicker and the less dry a food is, the easier it is to swallow. Avoid straws for people who have a delayed swallow or are eating too quickly. Straws can push liquid to the back of the throat quickly and cause choking and aspiration of fluid into the lungs. Encourage small sips of liquid if coughing is occurring. The main risk factors for aspiration are decreased interest in taking in nutrition (and being fed) and poor mechanical swallow without an adjusted diet. Table 8.5 details the interprofessional delineation around the roles of evaluation for feeding/eating skills.

Additional Self-Care Basics: Hygiene, Bathing, and Dressing

Always consider how to maximize independence when care planning for self-care performance. The secret is to allow enough but not too much freedom and challenge. A person-centered strength-based way to determine the person living with dementia's abilities is by providing them a simple familiar task. One useful idea is to create a three-step task with three objects. This concept, the 3x3 observational assessment, allows caregivers to estimate how much assistance a person will need. This informal screening informs caregivers how many actions a person can sequence independently and allows a caregiver to determine how many steps a person can complete during self-care. Look for clues of where the person needs help. For example, provide a washcloth, soap, and a cup at sink side. Ask the person to wash and rinse their face and have a drink of water. If the person completes independently, the caregiver can expect that a three-step self-care activity can be completed with set up of supplies, cues, and supervision. If the person cannot complete the 3x3, eliminate a step and a supply (provide a 2x2). In this example, provide washcloth and soap and ask them to wash their face. If this is not completed, provide a 1x1, provide a soapy washcloth and running water, and state "wash your face." If the 1x1 is not successful, guide the person through each step required. Knowing the amount of steps or directions a person with dementia can negotiate will allow the caregiver to provide the right amount of assistance and avoid doing too much or too little. Caregiver's understanding of the person's abilities, and recognizing overwhelming tasks and environments, is essential to success. By achieving the basics (self-care) with limited struggle, quality time can be spent with the person and in leisure activities that support quality of life.

Dressing

Although seemingly a simple everyday activity, dressing requires multiple skills including visual skills, motor planning, sequencing, initiation, judgment, gross and fine motor coordination, and balance. A person getting dressed needs to select clothes, dress in sequence, orient the clothes to the correct body part, and terminate activity when completed. Clothes must be climate appropriate, fit correctly, and be clean. In summary, despite appearing straightforward and easy, dressing requires activity from all over the brain. With this in mind, caregivers must discover the careful balance between assistance and interference. Table 8.6 provides examples of common dressing errors made by people with major neurocognitive disorders. For example, people cannot maintain health and dignity if they walk naked outside, wear a heavy coat in warm weather, or wear soiled or wet undergarments. From a differing perspective, people can wear outfits that do not match, two pairs of pants, or an inside out T-shirt without harm. Families and caregivers may feel that allowing a person with dementia to look disheveled or mismatched is an issue of dignity. Plans of care must take careful consideration of all perspectives and consider a plan that

Table 8.6 Common dressing behaviors in advanced dementia

Layering clothes
Putting clothes on backward
Putting arms or legs in the wrong clothing location
Skipping buttons/unable to use fasteners
Putting both socks on one foot
Only wearing one shoe
Putting soiled clothes back on
Rinsing soiled clothes in the sink and putting them back on
Dressing/undressing at the wrong time of the day
Dressing/undressing for the incorrect temperature
Undressing in public areas
Poor safety awareness or balance while dressing
Suggestions for common dressing behaviors:
Remove soiled clothing once person has undressed
Limit choices
Lay out clothes on a bedside table or on the bed
Make sure there is contrast between clothes and what they are placed on
Hand clothing one item at a time. State clothing item's name "Here is your shirt"
Guide the first step of dressing and then allow for independent completion
If people are attached to familiar style of dress (e.g., button-down shirts or ties), create easy adaptions such as adding Velcro behind buttons and a belt with a children's quick release buckle.

Original Table by Sarah Foidel, 2018

leads to a person living with dementia having as much autonomy and control over their choices and environment as possible while providing for the least amount of individual correction. This is a concrete example of shared decision-making and strength-based support to those living with dementia.

Oral Hygiene

Oral hygiene is often neglected in advanced dementia. Common strategies are routine, simple supplies, and efficiency. For many people with advanced dementia, simply placing the toothpaste on the brush, placing it in their hand, and guiding it to their mouth will allow the motor sequencing part of their brain to take over the task from that point. Other strategies include modeling (brushing your teeth next to the person with dementia), using motorized toothbrushes, and non-alcohol-based mouth washes. For some people with advanced dementia, brushing will need to be completed by the caregiver in a gentle manner. Talk quietly and use gentle motions to clean a person's mouth. Limit amount of toothpaste to minimize the natural urge to swallow. Swabs or a soft washcloth can be used to clean teeth as well. Oral health can be encouraged by drinking water and eating healthy foods. Water picks can also be useful tools. Poor oral hygiene can lead to dental pain, decreased social participation, and increased risk when someone aspirates food or fluids into their lungs. An important note is that a person who does not clean their mouth on a daily basis is at a higher risk for aspiration (due to swallowing pocketed food).

Toileting

One of the largest caregiver burdens is incontinence of bowel or bladder. It demands a change in caregiver role and quite frequently can lead to combative behavior. Incontinence is a leading cause of distress for in-home caregivers and a frequent problem in long-term care. A person living with major neurocognitive disorder will not understand the need for assistance and the invasion into their privacy. Resistiveness or aggression at this time is often a clear communication of fear. Despite assumptions, continence is quite achievable until the very last stage of the disease, excluding those with medical condition effecting bowel and bladder control.

One key technique for the person living with dementia is the establishment of a toileting schedule. People with advanced dementia should be directed, guided, and cued to use the bathroom every 2 hours while awake. However, assisting with toileting may uncomfortable or be perceived as an aggressive move from the caregiver. Additionally, having a person with dementia sit on the toilet for 15 minutes after meals will add to continence. Wearing underwear that has a familiar feel and style will also add to the sensory feedback to avoid incontinence. Most people strive to be continent; it is something most have done for all but the very beginning of their life, and the motor sequencing part of the brain maintains this information late into life. Increased pacing, irritability, and anxiety can all be a person living with dementia communicating their need to use the bathroom without the ability to get their need met. In the extreme, urinary retention and constipation can lead to severe agitation and aggression, and the caregiver should keep track of how often bowel movements occur. During dressing and bathing, a caregiver should watch for a distended or firm abdomen that may indicate a person with dementia is retaining, or holding urine, in their bladder. This can be a side effect of medication or indicative of a medical problem and immediate medical advice should be sought in the case of urinary retention. Bowel movements should follow the lifetime pattern of the person with dementia and should occur no less frequently than every 3 days. A doctor may recommend increasing fiber in the diet or medications to prevent constipation. Constipation is very common with many medications including pain medications. It is often overlooked in people with advanced dementia despite being the most frequent predictor of agitation. Again, the agitation is the person living with dementia communicating with behavior what they are unable to communicate verbally or with their own actions.

An important part of continence is also toilet hygiene activities. Table 8.7 discusses key concepts for maintaining continence in people with major neurocognitive disorders. Several action steps can be taken to encourage toilet hygiene completion independently including easy-to-access tissue, toilet papers, and warm wet wipes. People with dementia may need cues to wipe, or physical assistance. Approach should be slow, words calm, and realize that this personal activity can be perceives as a threat and invoke

Table 8.7 Maintaining toileting independence

Key concepts for continence
Keep bathroom doors open and lights on if the lighting is dim
Limit rugs around toilet or in bathroom
Hanging a sign with a picture of a toilet/ universal restroom sign can help guide people with advanced dementia
Declutter bathroom area.
Watch for *searching* behavior: pacing, grabbing at groin, irritability, or anxiety
Provide cues and guidance to use the toilet every 2 hours
Regular underwear is recommended.
Running water can help people urinate
Do not hover – guide to the toilet and help as necessary with clothing management and step back (let gravity and familiar environment lead the way)
Place toilet paper tissues within easy arm reach
Always guide to the bathroom after meals and before time of sleep
Monitor toilet hygiene – signs that hygiene is not being completed adequately include stuffing toilet paper in their pants, dirty hands post toileting, or finding rinsed underwear in the sink or garbage can
Consider cultural issues around toileting and considerations for gender of caregiver

fear and a strong urge to protect oneself by fighting. For those that are resistant, daily showers may be a more person-centered option.

Case example: not in public!
Thomas was a 67-year-old man with early onset Alzheimer's dementia. His behavior is escalating with disease progression including aggressive outbursts and restiveness to care. He often paces around the house and pounds on the door. His wife, frustrated with his actions, continually tries to keep him indoors. Recently he has had urinary incontinence issues and is aggressive with attempts to help with clean up. In the middle of the night, he has urinated in the bath tub and in potted plants.

Ambitiously, Thomas's wife invites family over for his birthday. After soda and a large dinner, Thomas' pacing becomes more rapid, and he is irritable with his son. He tries the exit doors and need redirection. He eventually punches the wall, pulls down his pants, and urinates in a vase in the living room. His wife and family are horrified!

His niece gently guides him from the room and distracts him by looking at sports magazines and talking in a supportive manner. When the family is calm, the niece explains that Thomas is not incontinent or inappropriate – he is disoriented and unable to find the bathroom or communicate his need to go to the bathroom. She suggests a regular toileting schedule every 2 hours and after meals to reduce agitation.

Especially for women with advanced dementia, urinary tract infections can be a concern. Bacteria growing in the bladder or associated structures can cause pain, irritability, urinary frequency, and drastic change in mental status. Because advanced dementia limits the ability to self-report symptoms of a potential urinary tract infection, it is important for a caregiver to watch for signs of sudden behavior or mental status changes. Examples could be sudden restlessness, resistance to use the restroom, or calling out and screaming during peri-care.

Also of important to remember is that people with major neurocognitive disorder, especially men, may attempt to urinate in places that are not the bathroom. This can include on potted plants, in garbage cans, off the front porch, or in the corners of a room. In the person-centered strength-based point of view, this is not incontinence but actually an effort to be continent. The person is searching for a place to urinate. Remove objects that may be tempting or provide a stimulus, and put a toileting schedule in place. Providing universal signing on bathroom doors can help guide the person living with dementia to the location of a restroom. In extreme situations, many caregivers have successfully placed buckets around the house or a bedside commode near the bed to provide a receptacle if a person with advanced dementia cannot make it or communicate the need to use the restroom in an efficient manner.

Bathing

Bathing creates an extremely vulnerable position for a person with advanced dementia. Preparation, planning, and scheduling are important. Consider lifetime habits of person with dementia – Did they prefer showers over baths? Were they modest? Did they take long or short showers? Did they wash their hair every day? Personal habits and routines are reflected throughout the lifespan and need to be respected as dementia progresses. Knowledge of previous preferences of the personal hygiene is an extreme help for care planning. Have warm towels ready, shampoo, and water set. Again the same principles can be applied as with other activities of daily living apply to showers and bathing. Consider the number of steps a person can participate in during an activity. This ability is usually seen globally across all ADLs.

Slowly introduce sensory stimuli change: temperature, the feel of water, undressing, and navigating into the tub/shower can all be overwhelming. Undressing outside the bathroom and putting on a robe before entering can minimize sensory overload. Allow the person with dementia to feel the water before entering the shower area. Help wash hidden or difficult to reach areas, but allow the person to wash their own body by providing a washcloth and guiding to begin the washing process. Helpful equipment includes a nonskid matt, oversized bath towels, tear-free shampoo, body wash, handheld showerhead, and bath seat. Showering can be a relaxing experience if provided in a slow and non-demanding manner. Encourage the person living with dementia to participate in every possible step. If irritation occurs, slow down and listen to what the person is communicating with their behavior. Give power back to the person being cared for. Place a washcloth in their hand or let the person lather the shampoo. Let go of expectations, and remain a calm guide through a necessary activity. Some people with dementia have a very hard time with showers no matter how person-centered they are planned. The following table has suggestions for people who are extremely

Table 8.8 Strategies for bathing challenges

Bathing techniques for the difficult shower/bath
Limit showers to when necessary
Manufactured no water shower caps from hospital provide a dry shampoo for those resistive to baths/ showers
Bed bath can be a great option. Have the person wear the robe and then slowly wash each body part at time with a warm basin and cloths. Keep the person warm and areas covered except when they are being washed
Consider glare and visual perceptual challenge of bathroom. Using contrasting mats, marking thresholds with waterproof tape, and limiting the glare of florescent lights can decrease fear of falling

uncooperative with bathing activities. Table 8.8 provides some straightforward bathing strategies that can decrease the stress or fearfulness that can be created by bathing activities.

Sexual Activity

Sexual drive and activity in older adults are often a taboo subject. With the addition of cognitive impairment in older adults, sexuality and sexual activity is rarely addressed. Humans as they age are still humans. The same drive for relationships and touch continues to exist. The drive for close personal relationships continues. However, typically aging adults usually deal with joint pain, vascular changes, changes in levels of sexual satisfaction, and complications from medications that influence sexual satisfaction (National Institute on Aging, 2018). Many people view loss of sexuality as normal aging. In fact, in a youth-oriented society, sexuality in older adults is often considered inappropriate or something not to be discussed [34]. Using a person-centered approach, practitioners must not make assumptions about a person living with dementia's sexuality or gender identification. For people with major neurocognitive disorder who enter long-term care, close personal relationships are quickly removed along with all of the other major changes that occur at the same time. Privacy is generally not provided to couples. Capacity for relationships is questioned by staff and family.

Often the question of sexually inappropriate behavior arises in long-term care. Like all behaviors, it must be seen as communication. Staff must go through the same decision-making process regarding care planning. Figure 8.2 model for care planning (also referred to in previous chapters) reminds the caregiver that all behaviors must be examined for unmet needs and emotional causes.

It is important for the caregiver of a person living with dementia to realize that all behaviors that may have *contextual sexual implications* (removing clothes in a public place,

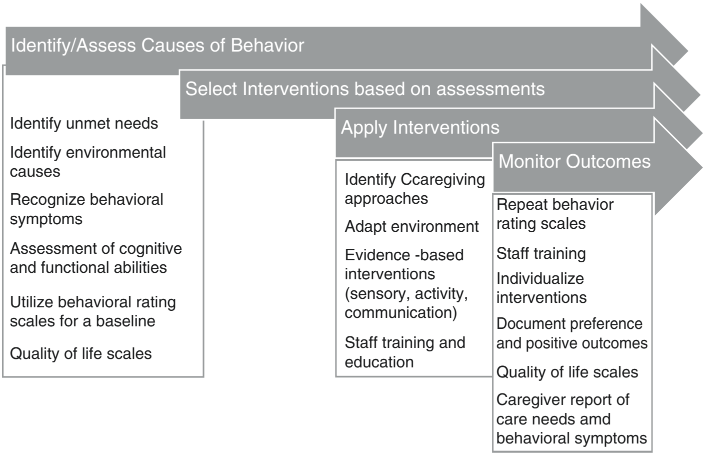

FIGURE 8.2 Person-centered plan of care. Also featured in Behavioral Interventions chapter. (Created for this text by Foidel, 2018)

reaching out in the shower) may not be *sexually inappropriate* behaviors. Reporting that a resident or person with dementia is sexually inappropriate can have a long-term negative impact on a person's life. Table 8.9 provides a contrast of behaviors often interpreted as sexually inappropriate though it is actually communication of an unmet need or natural response to the environmental stimulation.

How to Connect ADLS with the Assessment of Cognitive Domains

Using a strength-based assessment based on cognitive domains, individual ADL abilities can be identified. With a careful assessment, a trained health professional can identify the source of impairment leading to ADL difficulties and therefore develop a person-centered care plan. Table 8.10 describes common ADL problems and links back to cognitive domains.

Table 8.9 Differentiating behaviors

Behavior of person with dementia	**Unmet need or motivation**
Stripping in dayroom of long-term care	Person too hot or needs to use the bathroom
Urinating on plants in the dining room	Need to use the restroom
Climbing into bed with a peer	Searching out or mistaking peer for partner
Grabbing a caregiver in the shower	Misinterpreting personal self-care situation for a sexual relationship
Grabbing a peer sexually despite peer's distress	Monitor for possible sexually inappropriate/ predatory behavior
Masturbating in common area of long-term care	Disorientation, need for stimulation – redirect to privacy of room
Following one caregiver or peer and continually targeting with abusive or aggressive speech	Monitor for possible sexually inappropriate/ predatory behavior

Original Table by Sarah Foidel, 2018

Table 8.10 Strength-based assessment

Activity of daily living	**Deficits identified from assessment**	**Cognitive domain from DSM-5**	**Strategies**
Grabbing food from others plates and chugging coffee	Disinhibition Poor insight Poor ability to understand emotions from others (perspective taking)	Social cognition	Limited supplies Cups that have a slow pour spout Distance from others at meals Clear reminders for behavior at meals Modeling behavior

(continued)

Table 8.10 (continued)

Activity of daily living	**Deficits identified from assessment**	**Cognitive domain from DSM-5**	**Strategies**
Poor oral hygiene and failure to change dirty clothes	Poor short-term memory Poor orientation	Memory and learning	Regular routine Caregiver prompts to start activity Limit questions Cue to supplies and allow independence Environmental cues/calendars
Messy completion of ADLs and not completing thorough bating	Easily distracted Poor STM Difficulty focusing on conversation	Complex attention	Direct cues Limit supplies Assist with cueing throughout task

How to Create a Person-Centered Plan of Care

Person-centered care is defined as knowing the person being cared for; understanding their preferences, abilities, and history; and matching activities to these attributes. Forcing too much or too little care can lead to exhaustion, frustration, and behavioral (i.e., communication) issues. In addition to observing the person with dementia and providing 3x3 informal assessment, understanding a person's self-care history can really assist in making the care basics more achievable. The worksheet that follows is an example of information that could be gathered from a person with dementia, from observation, or from a loved one.

Worksheet 1: personal self-care preferences

Food preferences:
Do you like to eat breakfast?
What is your favorite food?
Do you drink a lot of water? Do you like it with ice?
Do you drink coffee or tea? How often?
What is your favorite food? What tastes do you like salty? Sweet? Sour?
What food do you hate?
Did you pack your lunch for work?
Do you like to eat dinners in a restaurant?
Do you drink alcohol? How often?
Do you have mouth pain? Is anything hard to chew?
Where do you eat meals?
Who eats meals with you?
Do you sit at a table?
What utensils do you use?
Dressing:
Do you where stockings? Tights? Socks? What kind?
What kind of shoes do you like?
Do you like to be barefoot?
Do you like T-shirts or button-down shirts?
What kind of underwear do you like?
Do you iron your clothes?
Do you like dress for comfort? Tell me how.
Do you dress for style? Tell me how.
How do you dress for religious events (if applicable)?
How do you dress for meals?
How do you dress for work?
How often do you wash your clothes?
Do you get hot easily?
Do you get cold easily?
Do you wear a jacket when you go outside?
Do you wear hats or headgear of any kind?

(continued)

Hygiene/Bathing

Do you prefer showers or baths?
How frequently do you shower?
What time of day do you shower?
Do you blow-dry your hair?
Do you wash your hair every time? If not, how often?
Do you use conditioner when you wash your hair?
Do you use a washcloth?
What body part do you wash first?
How warm do you like your shower/ bath?
Do you brush your teeth in the morning? In the evening?
Before or after meals?
Do you floss?
Do you use mouth wash?
Do you shave with a straight razor?
Do you shave with an electric razor?
How often do you shave?

In summary, careful attention to individualized need is key to building an environment for self-care success. Recommended approach is an individualized assessment, knowledge of history and routines, and caregiver access to person-centered care plan. This strength-based approach can add to quality of life for those living with dementia. Important concepts to remember include not over caring and replacing independence for caregiver satisfaction in task completion (e.g., caregiver bathing person versus maximizing autonomy, due to non-health-related hygiene concerns). The following Appendices A and B show an example of a person-centered plan around engagement in meaningful activity.

Appendix A: Occupational Therapy Individualized Care Plan Report

Occupational Therapy Individualized Care Plan Report

Background Information

Date of report: Client's name or initials:

Date of birth:

Therapists:

Reason for referral:

Occupational profile:

Individual and/or caregiver report of decreased occupational performance (self-reported goals)**:**

Assessments performed:

Findings and analysis (fill out the table below for summary of current occupational engagement):

Areas of Occupation	Level of Independence (observed)	Level of Independence (reported)	Reporter of information

Interpretation:

Areas of occupation (strengths and challenges)**:**

Behavioral/emotional concerns based on evaluation:

Priorities for intervention (at least three priorities):

Plan:

Targeted area of occupation	Baseline supports needed	Observable behavior to watch for when person is experiencing poor performance	Interventions to improve performance and decrease behavioral concerns

Specific client-centered activity recommendations:

Activity	Environment Support Recommendations	Supplies Needed	Frequency for Activity

Specific ADL recommendations:

Specific communication recommendations (give suggestions to staff and caregivers to support care of client)**:**

Recommend reassessment of resident (timeline)**:**

______________________________ Date

Reviewed by OTR/L

Appendix B: Example Occupational Therapy Individualized Care Plan Report

Occupational Therapy Individualized Care Plan Report
Background Information
Date of report: N/A Client's name or initials: XX
Date of birth: Patient unable to report
Therapists: OT
Reason for referral: Lack of engagement in meaningful occupations and difficulty transitioning.

Occupational profile:

XX is an older woman who lives in an assisted living facility. She enjoys sitting on a couch in the lobby (close to the window) and is welcoming to others sitting next to her for company. XX reports she enjoys conversing with others and independently moves chairs to talk with other ladies sitting in the lobby. She notes how she will not be a great conversationalist, due to her memory. XX short-term memory is impaired, but she is aware of her memory struggles and sometimes calls herself "stupid" or "idiot." One way she copes with this is by saying she doesn't like to live on memories and does not like to dwell on the past.

The staff at Happy Care guide XX, everywhere. The activity director reported XX has a routine of staying in the lobby for most of the day, attending meals, and then calling her daughters in the evening once she is back in her room. As people walked by, she became confused as to who was who. She thought she saw her daughter and asked if one man was the pastor. XX easily loses track of her thoughts and has a hard time thinking of what she wants to say. She gets up numerous times a day to ask the front desk when the next meal is or what she is supposed to be doing, unsure if she is in the correct place. Some information we obtained about XX's past includes:

- Picked hops in Independence XXX with her brothers and went to an all-girls high school.
- In the Air Force, she was a corporal in the Women's Army Auxiliary Corps, and she was stationed in Newport News Virginia for a time.

- Used to be a hairdresser.
- Likes getting her nails done.
- Loved drinking beer.
- Husband was an artist.
- She and her husband owned a Tavern in Oregon.
- She has two daughters, one of which lives in Oregon.

Room environment:

- Clear floors, with no tripping hazards.
- Television with Christian sermon on.
- Phone with raised numbers and high contrast to help with low vision.
- Digital clock on her nightstand, along with a water bottle and flashlight.
- Crossword books on multiple tables and shelves.
- Books and a deck of cards on a shelf in her living room.
- Pictures of loved ones on shelves.
- Walk-in shower with grab bars and a shower chair (receives step-by-step directions for all self-care tasks).
- Clothes are organized by type (i.e., short sleeve, long pant, etc.).
- Bedtime clothes placed on a chest directly in front of her bed.
- Many small objects in the cupboards, such as a headband, empty chip bag, and a wireless phone.
- Fridge filled with Ensure and water.
- Two types of signs inside room:
    1. What she should not worry about – placed in four different places in her room and is a pink paper with all capitalized black lettering; includes waking up in the morning, call at 6:30 am from Marilyn or staff will get her up; paying bills, daughter takes care of finances; laundry and sheets; taken care of by Happy Care staff; and people at Happy Care take her to meals, exercise class, and entertainment.
    2. Daily schedule in all capitalized black letters on white paper, stuck on her fridge.

Individual and/or caregiver report of decreased occupational performance: Lack of engagement in leisure activities and difficulty transitioning from one location to another.

Assessments performed: OT performed an occupational profile on XX and gathered information through interviewing XX, the activity director, and certified nursing assistants (CNA's). Considering the degree of XX cognitive impairment, informal observations were used as XX engaged in various activities.

<u>Findings and analysis</u>

Areas of occupation	**Level of independence (observed)**	**Level of independence (reported)**	**Reporter of information**
Leisure	Max cognitive, verbal, and physical cues	Max cognitive, verbal, and physical cues	Activity director
ADL	Max cognitive, verbal, and physical cues	Max cognitive, verbal, and physical cues	CNA's
IADL	Max cognitive, verbal, and physical cues	Max cognitive, verbal, and physical cues	CNA's

<u>Interpretation</u>

Areas of Occupation

Strengths:

XX has an extensive history in many occupations, from living in the country where she helped grow and pick crops to entering the armed forces and later becoming a hairdresser, as well as a wife and mother. These occupations can be used to guide activity choices for XX to engage in. XX also enjoys being with others and wants to converse and participate with the right guidance and reassurance.

Challenges:

XX short-term memory is her biggest challenge. At this time, XX is aware of her declining memory and inability to think clearly. She is easily flustered and gives up, unsure of how to complete a task and concerned with doing tasks correctly.

Behavioral/emotional concerns based on evaluation: The anxiety and decrease in confidence due to XX's awareness of her severe short-term memory loss are her most significant concerns.

Priorities for intervention:

1. Task transition
2. Leisure engagement
3. Sustained independence in ADLs and IADLs

Plan:

Targeted area of occupation	Baseline supports needed	Observable behavior to watch for when person is experiencing poor performance	Interventions to improve performance and decrease behavioral concerns
Transitions	Max cognitive, physical, and verbal cues	Saying she does not want to get up from couch and that she cannot do "blank" anymore Starts stuttering and cannot get clear words out in response to your question or statement	Introduce yourself, sit down next to her, and then say she should come with you to go check out when lunch is or to see if there are cookies at the front desk If this does not work, wait until she gets up on her own and say, "Let's go check out when lunch is" and then when you see no one is in the cafeteria say, "Let's go check out ___" or "Let's go walk to ___" Give her cues as you are walking, such as "We are going to the elevator" or "We are going to turn right"

Targeted area of occupation	**Baseline supports needed**	**Observable behavior to watch for when person is experiencing poor performance**	**Interventions to improve performance and decrease behavioral concerns**
Leisure	Max cognitive, physical, and verbal cues	**Sitting in lobby:** getting up and asking front desk about where to go or what to do; always asking about next meal; looking at her watch; asking if she should get into car outside; looking at her key and stating room number; concerned look on her face (furrowed brows) **One-on-one activities:** Puts down/ takes out of hands and stops engaging; says she cannot do it because of hands (holding them up and looking at them)	**In the lobby:** Have a table next to her with the following items: 1. Sign with her name, indicating the objects on the table are hers 2. Sign that indicates when next meal is (i.e., lunch 11:00 AM) 3. Picture that shows how to use nail file and nail cleaner with actual tools directly underneath it 4. Large font crossword puzzle book with one pencil directly next to it **During one-on-one activities:** 1 step cues Smiling, thumbs up, and touch back or shoulder when guiding her through hallways Words of encouragement and affirmation, such as “You are doing a great job!” or “Thanks for being such a big help!”

Targeted area of occupation	Baseline supports needed	Observable behavior to watch for when person is experiencing poor performance	Interventions to improve performance and decrease behavioral concerns
ADLs	Max cognitive, physical, and verbal cues	Puts down/takes out of hands and stops engaging; says she cannot do it because of hands (holding them up and looking at them).	Provide step-by-step verbal cues and demonstrate when needed Encourage and reassure!
IADLs	Max cognitive, physical, and verbal cues	Same as above	Same as above

Specific client-centered activity recommendations

Activity	Environment support recommendations	Supplies needed	Frequency for activity
Exercise group	When she gets up around 10 am to ask when lunch is, go check out the lunchroom with her, but then say, "Let's go check out the group activity" and guide her upstairs Provide her a chair in the front row and sit in a chair beside her to demonstrate, allowing her to imitate your movements. She will need encouragement (i.e., smiling, nodding, thumbs up) and minimal physical assistance in beginning more complicated movements, such as stretching arms across body	None (chair is located at class)	At least 3x per week

Activity	**Environment support recommendations**	**Supplies needed**	**Frequency for activity**
Shelling snap peas or peeling onions	Saying, "The kitchen could use some help with these," demonstrate shelling one of the peas, and then hand one pea to her Short, simple words of encouragement and affirmation, such as: "This is a huge help," "Thank you for showing us," and "I can tell you've done this before" **Grading down:** Peas: opening the peas for her, and then hand them over for her to put into a bowl Onions: start peeling and then hand it to her to finish	Snap peas or onions and two small, brightly colored bowls	As often as possible: this activity requires one-on-one cueing and encouragement

Activity	**Environment support recommendations**	**Supplies needed**	**Frequency for activity**
Cleaning underneath fingernails and filing nails	"I know you like to do your nails. Here is a file (or a nail cleaner stick)." Demo how to use the tools (with her own nails), and then place the tool in her hand. If she does not want to use them, set them next to her on the table for her to self-initiate later	Nail file and nail cleaner (wooden)	Daily, while sitting on couch in the lobby
Sorting coins **Similar activity to try:** sorting silverware or colored buttons	Set up the bowl of coins directly in front of XX on the table and have the other bowls surrounding it Demonstrate what you would like her to do and then hand her a coin. Provide verbal and physical cues (i.e., encouragement, and pointing to the bowl with the coin she is searching for if she verbalizes she doesn't know)	A variety of coins in a small bowl Four small, colored bowls to use as she separates the coins	As often as possible: this activity requires one-on-one cueing and encouragement

Activity	**Environment support recommendations**	**Supplies needed**	**Frequency for activity**
Crossword puzzles	Place next to her on the table in the lobby. Let her know the book is hers as you set it down	Large font crossword puzzle book from her room	Daily, while sitting on couch in the lobby

*Having music playing in the lobby: XX's foot was tapping, and she crossed her legs showing relaxation and comfort while sitting on the couch.

Specific ADL recommendations:

In the morning before she goes down to the lobby, make sure she has:

1. Watch on her wrist
2. Keys on her wrist
3. Glasses around her neck
4. A bottle of Ensure or water

Health literate signs: Colored pictures with minimal font (black letters, 14+ size) on white paper, in her bathroom and bedroom, outlining steps to get ready in the morning/night.

Specific communication recommendations:

1. One step cues; calming, short phrases of affirmation, comfort, and encouragement.
2. Hold her hand and/or touch her back or shoulder when speaking to her/guiding her from point A to point B.
3. Food is a motivator! Use that to transition her from one activity to the next.

Recommend reassessment of resident: Recommend reassessment in 4 weeks to follow up on ease of task transitions and level of occupational engagement.

______________________________ **Date**

OT

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Chapter 9
Person-Centered Care and Care Planning for Those with MNCD

Sarah E. Foidel, Maureen C. Nash, and Susan S. Rose

Person-Centered Care and Care Planning

The fundamental philosophy underlying person-centered care is to create a human relationship between people living with neurocognitive disorders and those who care about and for them (both family and care providers). The personal, rather than clinical, relationship is central to creating a paradigm shift in how we care for people living with dementia. This relationship extends to the family and other natural supports of those living with dementia.

The philosophical notion of being present – human to human – and understanding another's experience is central to caring for those living with dementia. Often people living with dementia struggle to share who they are as a person and

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require assistance of healthcare providers to develop a trusting relationship. Ideally, the care plan is a living document written from the person living with dementia's viewpoint, outlining the person's goals and steps the person, their family, and professional staff will take in efforts to meet them.

The care planning process enables the interdisciplinary team to understand a person's desires and needs, and the care plan document offers a vehicle to communicate with the person living with dementia and their family. Every care plan should be individualized and focused on meaningful engagement. Care should be relationship-based, with an emphasis on promoting a positive engagement. Information needs to include the person's physical needs, personal values, daily routines, sources of meaning, and enjoyment. When someone has moved from their own home into a facility, a care plan and staff training are required to assess staff needs, resources, satisfaction, and person-centered communication abilities [12].

Provider-based treatment plans as seen in Table 9.1 are based on a medical model. Patients present with symptoms, syndromes, and diseases, the provider performs an assessment and develops a working diagnosis which leads to the plan. The viewpoint is the clinician's, and the language is specific to a specialty of medicine. The assessment and plan are written solely by the provider. Nursing care plans, rehabilitation care plans, and others use an analogous model. The patient is passive, while the clinician acts on the patient.

TABLE 9.1 Provider-based treatment plan

Problem	**Task/plan**	**Staff**	**Time**	**Outcome**
Chronic pain	Oxycodone	PCP	QID and PRN	
Sleep disturbance with limb movement disorder	Trazadone	PCP	Q hs	
	Lorazepam	PCP	Q hs	
	Sinemet	PCP	Q hs	
	Monitor sleep	Self	PRN	

Treatment teams, such as inpatient psychiatric care and inpatient rehabilitation units, often include a multidisciplinary team (MDT). The MDT members each perform assessments from their own discipline's perspective and contribute individually to the treatment of the patient. MDTs then develop a treatment plan, which consists of diagnoses or problems, and each discipline addresses the problems separately. Generally, every member of the MDT signs the treatment plan which is then presented to the patient for their signature, although there is little or no negotiation with the patient. The MDT model is similar to the provider-based model, but with a greater number of disciplines. A true interdisciplinary team (IDT) model integrates the MDT model into a matrix of collaboration, as discussed in an earlier chapter in this book.

In contrast, service-based plans are frequently used in assisted living facilities (ALF), underscoring the view of the individual as a customer. Commonly, a service plan has a column with particular services to be provided to the person living there: nursing services, medication administration, dining room services, laundry services, etc. This is followed by a column listing the frequency of the service, who will provide the service, and sometimes a space for individual information or comments. The service plan is set up to easily tally the cost of the package of services being delivered to the person living there. Generally, a manager will sign the service plan as well as the ALF resident. A resident has certain rights and can negotiate some aspects of the service plan, but ultimately the management has final decision-making power as landlords.

Person-centered care planning, an example of which is in Table 9.2, is required by federal regulation in nursing facilities. The authors of this text recommend that every person living with dementia will benefit from having their own personalized care plan. This document can be used as an aid to communication between the person and family as well as introduction about the person for professional caregivers and clinical staff. Ideally, those living with dementia will have access to an IDT with whom to collaborate for their care

Table 9.2 Person-centered care plan by an interdisciplinary treatment team

Person's goal	**Plan**	**Outcome monitored/ discipline**	**Met? Circle one**
Pain-free	Hydrocodone Stationary bike exercise Massage	Reports 3 or less on pain scale >50% of time (RN) Activity director arranges ride to gym and massage (AD) Person reports satisfaction with pain mgmt (SW, PCP, RN)	Yes/no
To get a good night's sleep	Walks for 10 minutes 3 x/day Develops sleep hygiene bedtime ritual	Reports feeling rested two or more times per week (PCP/RN) Assist with sleep hygiene (AD)	Yes/no

planning as outlined in the earlier chapter on IDTs. The members of a person's IDT will vary depending on their particular needs, where they live, and what resources are available. The key to a high-functioning IDT is the collaboration and combination of insight and thought leading to planning that supports the decisions of the person living with dementia, utilizes their strengths, and meets the needs of the person.

Person-centered care for those living with dementia is most effective when care is informed by individual strengths. The role of the care plan and the care planning process is particularly important for those living with MNCD. First, this group of individuals has a limited ability to speak for themselves, particularly when undergoing a transition. Second, the ability to communicate verbally is likely to decrease over the course of the disease process. Finally, neuropsychiatric symptoms place the individual living with dementia at elevated risk of needing a higher level of care due to increasing care needs. When the person arrives with their current care plan, the ability to orient and engage the person at admission to a new facility or when starting with a new provider will be greatly enhanced.

Cultural influences, personal motivations, and meaningful activities must all be considered. When first introduced, patient-centered care was viewed as practitioners seeing patients as individuals and empathizing for the unique perspective and experience [1, 13]. The initial development of person-centered care has evolved into the direct connection for care planning and training caregivers of persons living with dementia.

Additional studies support caregiver training and patient-centered interventions that directly target common neuropsychiatric symptoms. Agitation, a neuropsychiatric symptom sometimes driven from unmet needs, has been shown to be decreased with person-centered activities and treatment plans [5]. Doody et al. [21] report grading tasks, toileting schedules, and cues to complete self-care as a best practice approach for dementia. Kverno et al. [11] concluded that individualized schedules that assist with arousal states and environmental adaptations are the strongest interventions in a systematic review of non-pharmacological interventions for people with advanced dementia. Spijker et al. [20] recommend consistent caregiver intervention with high ability and intensity to delay institutionalism. Caregiver training has been shown to be the most recommended approach to provide care for people living with dementia [8, 11, 22].

Person-centered care has several essential elements: understanding individual life history and needs, knowledge of family and other natural supports involved, providing meaningful activities, and adapting environmental demands [10, 14]. In the model proposed in this book, evaluation of strengths is conceptualized as rooted in skilled evaluation. After an evaluation is completed to identify a person’s life history, strengths, challenges, and current supports, a care plan should be developed based on the causes of neuropsy-

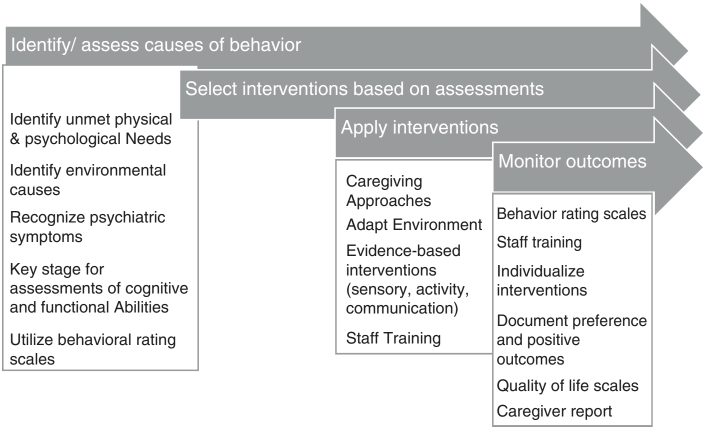


FIGURE 9.1 Model of care planning: strength-based. (Figure created by Sarah Foidel, 2018, for this text)

chiatric symptoms and personal motivations for engaging in meaningful activities. Figure 9.1 outlines a clinical reasoning process for care plan development. Integral to this model is staff education, use of quality of life measures (not just poor outcome measures), documentation, and continued regular review.

In a comprehensive review of guidelines published after 2009 around person-centered guidelines, Maloney [12] noted six areas where routine assessment is recommended: cognition, functional status, neuropsychiatric symptoms, medical status, living environment, and safety. Recommendations about frequency of assessment and reassessment of NPS are varied but generally recommended every 3–6 months and when there is a notable. Functional and medical assessments are recommended every 6–12 months and whenever there is an increase in NPS [12]. Other areas that are recommended for routine assessment include goals of care, driving, home safety, and use of substances [3]. The authors of this text recommend that every IDT's care planning start with the goals of care for a person. It is essential that all assessments and interventions take the individual's goals of care into consideration.

Identify and Assess Neuropsychiatric Symptoms and Interpret the Communication Embedded in Behavior

Neuropsychiatric Symptoms (NPS) Versus Psychiatric Illness

As reviewed in earlier chapters, NPS are ubiquitous in those with MNCD. The importance of distinguishing between symptoms and illness should be underscored. Those individuals with a history of significant mental illness such as schizophrenia, bipolar disorder (BD), and major depressive disorder (MDD) have a significantly higher risk of developing MNCD than the general population [4, 9]. Therefore, the care plan is essential to provide a past history of illness, as well as vital information on how the episodes have presented in the past.

The importance of the individual care plan is essential for individuals with concurrent neurocognitive and psychiatric illness. The standard of care for psychiatric illness must be at the forefront of care, even if there is a potential conflict with institutional or regulatory guidelines. The pressure to decrease unneeded psychotropic medications in those with MNCD is appropriate overall but may cause unintended consequences for individuals with concurrent psychiatric illness. The current focus is only on what the percentage of use of a class of medications. This is misguided and the opposite of individualized and person-centered care. The goal should be appropriate use and nonuse of medications. Avoiding the use of a needed medication because CMS publicly reports the percentage of people being given that medication is diametrically opposed to person-centered care, the right medicine to the right person at the right time, and the right intervention to the right person at the right time – this is the triple aim of modern healthcare.

For example, the current standard of care for treatment of recurrent major depressive disorder (MDD) recommends indefinite treatment with the antidepressant regimen that enabled them to be stabilized. In some cases, the mediations may be tapered, but the individual with MDD will still require monitoring for at least 1–2 years and perhaps longer. This individual's care plan will therefore highlight the need for these medications to remain unchanged, unless there is a pressing clinical concern. This is not the person for whom a routine gradual dose reduction (GDR) is likely to succeed; in fact, an unaware or routine reliance on GDR protocols may directly cause psychiatric decompensation, extreme suffering potentially including suicide, loss of placement, loss of friendships and other relationships, financial hardship, etc.

Similarly, someone with schizophrenia generally should continue on antipsychotic medications for at least 5 years after their last symptoms [2], which may potentially conflict with institutional guidelines for GDR. If all symptoms are not in remission for 5 years, then GDR is contraindicated. If symptoms reemerge after medication doses have been lowered or discontinued within the last 5 years, antipsychotic medications must be restarted or titrated back to previous doses. Individuals with preexisting psychiatric illness deserve to have their illness treated without exposure to the risk of suffering that accompanies decompensation simply because they also have dementia or have to live at a certain level of care.

Anxiety can serve as both a symptom and a disorder. Anxiety is a common neuropsychiatric symptom affecting individuals with MNCD. Anxiety is also a class of several disorders, as seen in illnesses such as generalized anxiety disorder (GAD) or panic disorder. Assessment and treatment of anxiety as an NPS is clinically different than assessment and treatment of an underlying anxiety disorder.

When an individual living with MNCD also has an underlying anxiety disorder, symptoms of anxiety should be evaluated in that context. If the symptomology is like past episodes of the anxiety disorder or meets current criteria for a particular anxiety disorder, then it would be reasonable to treat the symptoms as a relapse or occurrence of the underlying disorder, including a trial of medications that have been useful in the past. On the other hand, anxiety can occur as a nonspecific reaction when the environmental demands and expectations exceed a person's abilities, which is quite common in individuals living with MNCD. People living with dementia also experience anxiety when feeling overwhelmed about the changes in their brain functioning. These types of NPS-related anxiety symptoms are often best treated supportively with environmental modifications, supportive care, and reassurance. Dementia-specific medications can also be helpful for this symptom when it is caused by the MNCD rather than a specific anxiety disorder.

Similarly, depression serves as both a symptom and a disorder. Major depressive disorder (MDD) is common in the population as a whole, particularly in women. Depression as a single symptom is also a common NPS in those with MNCD and occurs frequently in individuals with vascular dementia as well as MNCD due to Lewy bodies or Parkinson's disease.

Psychiatric medications have less utility in NPS, as most medications have been designed and tested in younger adults with specific psychiatric illnesses and syndromes rather than in older adults with MNCD. For example, antidepressants are an important part of treatment for MDD but less helpful for depression as an NPS. Symptoms of sadness and grief are common human emotions and will not respond to an antidepressant.

There is evidence for use of psychiatric medications for some NPS. This needs to be reviewed individually. Some NPS in MNCD respond to dementia-specific medications, while others do require psychiatric medications. All NPS occurring in those living with dementia do arise from the neurological system as do all psychiatric illnesses. A clear diagnosis and plan for a medication trial includes monitoring symptoms, preferably with a formal scale such as the NPI-Q, stopping medications that are not helping and routine monitoring of side effects. All medication use, psychiatric and otherwise, requires an informed consent process. Risks and benefit calculations for a person will be affected by the person's particular goals of care [19].

Recognizing Communication Embedded in Behavior

It is important to observe and describe the behaviors exhibited by individuals living with MNCD. Behavior is communication, and recognition and categorization of behaviors enables interpretation of the message. As described in the chapter on pain, physical distress is commonly expressed by crying, pacing, clenched fists, and hitting and pushing caregivers. Similarly, anger and aggression may reflect fear or shame [17, 18]. Looking for the underlying emotional expression is an essential part of the evaluation process. The individual with MNCD may be exhibiting characteristics of anger, but the clenched fist may actually be driven by fear, pain, confusion, etc. Dealing directly with the fear is a better strategy and much more likely to succeed than focusing on the anger itself. Exploring the accompanying emotional expression is imperative.

Identify Unmet Physical and Emotional Needs

Neuropsychiatric symptoms provide a way to communicate unmet needs for individuals living with dementia. Caregivers should be encouraged to identify all basic needs when trying to decipher behavior as communication. Physical needs include hunger, thirst, need for toileting, and relief of pain. Emotional needs may include searching for familiarity, seeking safety, and looking for meaningful activity or human contact. This has been explored in the earlier chapter on ADL care. That chapter was a guide showing how to use the strength-based person-centered interdisciplinary approach to care for a person living with dementia.

Drive for Meaningful Activity

Most people fill their days with productive work. Work is not exclusive to earning a wage and includes activities such as pet care, child rearing, housekeeping, or cooking [23]. Dementia potentially robs the individual of the ability and skills to participate in meaningful activity. To fully understand this devastation, the caregiver must understand that dementia is much more than memory loss; rather, it affects all parts of the brain. As described in previous chapters, all cognitive domains are needed to carry out daily tasks. It is commonly assumed that if a person has done something all their life, they will *remember how* to do it. For example, a gardener will remember how to plant, a housekeeper will remember how to clean, and a mother will know how to cook a family meal. However, the process of remembering is not the sole problem with advanced dementia. The caregiver must understand and appreciate the complexity of the various skills required for completion of a task. With advanced dementia, the gardener may enjoy the feel of the dirt, but may not be able to understand what he sees. The housekeeper may continually scrub the counter, but not understand the use of supplies or results of her actions. The mother may unable to start the task or sequence the actions required to cook the traditional meal.

The inherent drive to be engaged in the world is an essential, universal part of being. Although the definition of meaningful activity may change, it is essential for people living with dementia to remain as active and connected as possible [15]. It is also essential that caregivers view activity as meaningful [16].

Cognitive dysfunction may affect skills, but the drive for familiar and purposeful activity persists. The gardener may pull out plants, the housekeeper may scrub a clean wall with a shirt, or the mother may become frustrated and throw ingre-

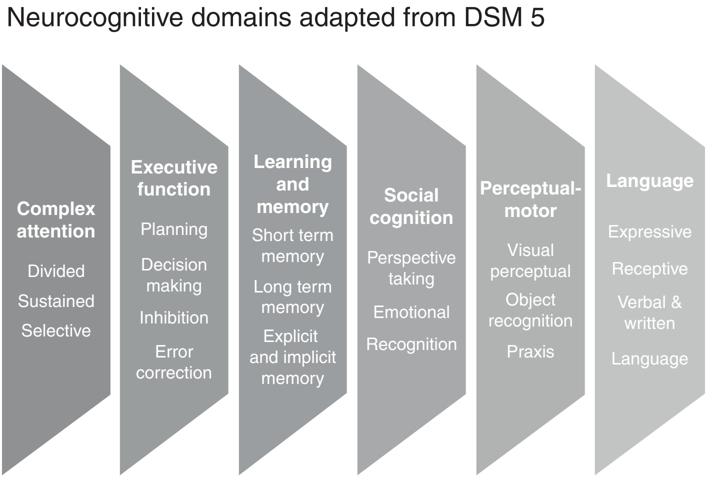


FIGURE 9.2 Cognitive domains as defined by DSM-5. (Figure created by Sarah Foidel, 2018, for this text. Adapted from DSM-5 criteria (American Psychiatric Association 2013))

dients on the floor. How the caregiver views and supports these activities can create meaning and transform them into purposeful activities.

Cognitive Domains and Strength-Based Assessments

The DSM-5 cognitive domains outlined in Fig. 9.2 provide healthcare providers with a common language to describe and communicate about cognitive domains. By understanding assessments from this point of view, health professionals can complete an evaluation that is strength-based, as well as identify interventions that meet the needs of the skill loss that is driving the behavior or challenging activity participation. Chapter 4 of this text provides an in-depth review on how to use cognitive domains to arrive at strength-based assessments for person-centered care.

Applying Interventions

As a caregiver, it is important to encourage participation in activity that follows the habits and routines that existed prior to the onset of dementia. The following are some simple ideas that can encourage productive activity in people living with dementia:

- Avoid power struggles.
- Choose engagement over expectation.
- Simplify and understand activity demand.
- Understand evaluation and progress.

Avoid Power Struggles

Simply stated, a caregiver will never win an argument with someone living with dementia. The same neurocognitive process that affects memory and executive function also affects insight. The greater the neurodegeneration, the greater the dysfunction. If the individual living with dementia is unable to comprehend their own behaviors or actions, it is unlikely that they are able to comprehend feedback about the rightness or wrongness of those behaviors or actions [7]. Constant redirection or feedback is therefore perceived as negative.

The distress of living with dementia can be analogous to constantly negotiating an unfamiliar and challenging environment. It is essential to teach caregivers to create safe and structured environments in which the autonomy of the individual with MNCD is supported. An environment that is set up to allow ample participation in activity decreases the need for redirection. Limiting the need for caregiver interference can decrease caregiver burden [6]. An important caregiving philosophy is the understanding that the person living with dementia may not be capable of change, but the caregiver is.

Case Example John: Occupation Stations

John is a 74-year-old male with vascular dementia. After suffering a series of strokes, John presented with loss typical of damage to the parietal, temporal, and frontal areas of his brain. Because of this damage, motor planning, sequencing familiar task, and language skills were lost. Despite some memory skills, his perceptions of sensory stimuli were distorted. Aphasia (impaired language ability) and apraxia (inability to sequence steps for an action) were profound. Self-care could be completed as long as supplies were simplified and routines were cued. In returning from the hospital, he was unable to work a remote control, answer a telephone, or work in his garden. An avid outdoorsman, he loved to fish. He also loved puzzles and prided himself in keeping the house clean alongside his wife. Due to subcortical damage, sleep regulation was difficult for John, and he could not keep track of time. Unable to read a clock, he was focused on time and schedules. He would often get up in the middle of the night and dress. Still mobile, he had unsteady gait and poor endurance. Scared of injury from falls and wandering, his wife sought a home safety evaluation.

John was friendly, but frustrated. He allowed the therapist to complete a home assessment. He appeared to enjoy the conversation, but was irritated with word loss and often would hit his fist on the table. He showed some emotional deregulation, with tearfulness and then laughter. The occupational therapist identified John's main concern was the loss of meaningful activity. His wife's main concerns were safety, specifically falling or getting lost. John was frustrated with his loss of abilities and believed his wife trying to control him. In effort to increase John's occupational engagement, the occupational therapist set up occupation stations within walking distance from his bedroom. He had frequent places to sit, *had limited hazards, and could move from station to station without falling. In one corner there was a simplified area to tie flies with feathers, string, and objects to sort in large tackle boxes. In the next area, there was a half-done puzzle with large pieces and reader glasses. There was an area to stack, move, and look at magazines in familiar topics with pictures. Mail addressed to him was placed on a desk as well was a large planner that had no appointments marked in the today slot. There was no easy path to the door, and all locks were installed high on the doors and painted the same color. The bathroom door was left open. The bathroom was free of clutter but with grab bars and a night light.*

Many nights, John would get up and move from station to station engaging in familiar, yet simplified, activities without falling and without the need of his wife to supervise or assist.

Choose Engagement over Expectation

Dementia is a progressive, terminal illness that places high demands on caregivers. Permission to enjoy time with the person living with dementia is essential for everyone's well-being. Many caregivers have an expectation of task performance. For example, if they cook with a person with a dementia, there is an underlying belief that the process should not be a mess and the food should taste good in the end. There is an *expectation* of a good product from activity.

Caregivers can decrease this frustration by learning to perceive activity as a journey. Viewing activity as a process to be enjoyed, or a road trip without a destination, can change the meaning of an occupation. If a caregiver is too busy looking at a map for a place that does not exist, they will miss all the scenery along the way. Professional caregivers need to be given permission to build relationship with individuals and engage in person-centered care.

Creative Janet: Too Many Cooks in the Kitchen

Janet's husband, Walter, was caring for her without assistance in the home. Janet had been diagnosed with Alzheimer's dementia for 7 years. She no longer kept track of days or remembered the age of her children and would wander without supervisions. Over the past year, Walter had to be home 24 hours a day and assist Janet with self-care tasks, such as picking out clothes, hygiene in the shower, and nutrition. Janet had always been a homemaker and made the meal, so cooking was new to Walter who was frustrated by her spilling and mixing of odd foods. Walter was devastated by the decline in Janet's function and her loss of skill, as she had always been such a good cook. Frequently, Janet told him his food tasted horrible and tried to help in the kitchen. She became angry at Walter for interfering with mixing and creating food. She yelled at him for not shopping and buying the correct items. He would not let her use the stove.

During a family visit, Walter and Janet's daughter brought premade pie dough. She spread the flour on the counter and asked for Janet's help. Janet immediately began to knead and roll out the piecrust. Laughing and talking, the flour got on her face, the floor, and both their clothes. Janet tasted the piecrust and said it needs more ingredients. She began adding as she saw fit, rolling and pressing the dough. Quietly, Dorothy put a pie together next to her mom and set it in the oven with her mom's approval. As the kitchen smelled like pie, they pressed the overhandled piecrust in a pan and set it aside. Out of sight and mind, they cleaned together as the kitchen smelled like pie. Walter was amazed by the amount of laughter coming from Janet and how happy she appeared as the pie came out of the oven.

Simplify and Understand Activity Demand

Underestimating the steps to complete an activity is a common occurrence and can lead to distress. Congruently, overestimating the ability of a person living with dementia can lead to an increase in neuropsychiatric symptoms. Dementia often looks good but performs badly – meaning that persons living with dementia do not look impaired and often surprise caregivers with their lack of ability. Persons with advanced dementia often lose insight and can overestimate their own abilities. Confabulation, filling in the blanks, and trying to make sense of the world during conversation can mask the true level of confusion. When persons with advanced dementia attempt to carry out a functional activity with multiple steps, the impairment may become more evident. The key is to find the just-right challenge. The *just-right challenge* identifies an activity demand where a person with cognitive impairment can participate in a meaningful way.

To identify the *just right challenge* consider a quick functional evaluation. As seen in Table 9.3, utilize the informal 3 × 3 assessment. Start by providing three objects and three steps, and observe how the person negotiates a familiar and interesting task. For example, if cooking is an interest, provide them with pot, a can of soup, and a can opener. Clear

Table 9.3 3 × 3 assessment: informal look at grading an activity

Cleaning: Provide spray bottle, cloth, and surface. Ask to clean the counter

Cooking: Provide two kinds of fruit and a butter knife. Ask to make a fruit salad

Gardening: Provide a pot, soil, and small plant. Ask to pot a plant

Home improvement: Provide a wooden box with pre-drilled holes, screws, and screw driver. Ask the individual to put it together the counter and ask for their help. Watch as they negotiate the tools and objects. Can they name them? Can they use them in the right order? Can they initiate and terminate activity? If it is too difficult, try to simplify and provide a 2 × 2 assessment, comprised of two steps and two items, and an invitation to "open the can and pour it in the pot." If it is too difficult, lower the complexity to a 1 × 1 assessment, such as "stir the soup." Take note of any observed frustration. A consult with an occupational therapist can assist in identifying the just-right challenge as well as completing an activity analysis on familiar tasks.

Creating A Fancy Garden: The Work Is Never Done

In developing a therapy garden at work many years ago, an occupational therapist started with a small chunk of grass that was turned into a manicured ADA accessible site with wheelchair accessible paths, sensory gardens, and raised beds for horticultural therapy activities. The therapeutic value of the garden was expressed in presentations that focused on how persons living with dementia could escape the institutional walls of the hospital and experience the calmness and healing power of the garden. When opened, it was beautiful.

As time passed, staff discovered the majority of the participants were too confused to participate in purposeful gardening. They would pull out flowers, water the sidewalk, and climb the fence. The garden slowly looked less manicured, less presentable, and less inviting to families and visitors. However, that is where the real work began. In taking people with advanced dementia outside simply for fresh air and exercise, the staff discovered it mimicked a run-down backyard. Older gentlemen with moderate levels of dementia could not resist the urge to pick up a rake or broom and begin to clean up. Others began pulling the dead heads off of flowers, putting on gardening gloves, and watering dying flower pots. People had long conversations about work to be done. People painted fences. People moved pots. Sometimes we planted and pulled things out in the same day. It was not the power of nature. *It was the power of occupation*. For those with memory loss, many do remember working. They remember working in their yards and chores that were never done, so they saw work and began to engage.

Consider setting up unfinished projects that might inspire people living with dementia to engage in meaningful tasks.

Activity becomes purposeful when an individual perceives that they are accomplishing something. Product is not important living with dementia, process is. Caregivers must be taught to let go of expectations that work will produce product or that all actions will be goal-directed. Taking apart an already broken appliance in a garage may be quite enjoyable to an individual with a mechanical tendency. The same activity may produce distress for an individual that is not mechanically inclined.

Concentrating on past interests and skills may provide opportunities to participate in similar activities. The trick is to simplify yet retain the meaning. For example, a post office worker may become enthralled with stacking and sorting mail. In contrast, an artist does not necessarily want to use crayons in a child's coloring book. Presentation of activity is essential. The provision of activities that allow for perceived independent choice increases occupational engagement (Table 9.4).

Person-centered care plans contain a number of components. Each clinical discipline will do an assessment and develop a person-centered plan based on their discipline's requirements and the standard of care. The care team will then meet together with the person living with dementia, the family or natural supports, and all the team members. Discussion centers on where the person has "travelled" in their life and their disease since the last care plan meeting, what the current state of the person is, and what the future is likely to hold. This is the time for every team member to contribute information about any challenges that may be occurring and for sharing strengths and resources that are appropriate for the person. The person living with dementia and family are provided the

TABLE 9.4 Positive environmental changes to encourage activity

Natural light and timing. Avoid dark rooms or dim working areas; light will encourage alertness and participation
Clean up the clutter – unless you want cleaning to be the occupation
Leave out tools in a simple manner that should be used; lock up tools that should remain untouched
Arrange furniture to encourage a flow of traffic. Close doors to rooms that do not need to be accessed. Make frequent rest break areas
Add context to workspaces by only leaving related items in eye view. Do not leave out more than three supplies at a time (e.g., a desktop, paper, one pen, and an envelope)
Environmental cues can assist in directing attention. Murals on doors can disguise exits. Stop signs can discourage entering rooms of the house that are not safe for people living with dementia
Remove trip hazards – rugs, cords
Cover outlets
Pad covers on sharp edges of coffee tables
Remove wheels from rolling chairs
Lock up medications, cleaning supplies, and nonedible liquids
Provide themes to rooms. Simple cooking in the kitchen, reading in the dining room, playing chess at a table in the living room
Setting up activity boxes or kits can create a quick opportunity for occupation. A box with jewelry and cleaning supplies can be quickly set up as an activity, for example
Do not provide more supplies or steps than a person is able to complete

opportunity to ask questions and dialog with team members. The interdisciplinary care plan is negotiated, signed, and disseminated to the person living with dementia, their family, and the team. Regular reassessments and updates to the care plan are recommended and if there is a significant change in the person's condition.

Appendix A: Sample Interdisciplinary Care Plan

Background Information

Date of report: January 12, 2019 **Client's name or initials:** AM

Date of birth: 6/24/1934, although patient is unable to report

Reason for care plan update: Change in condition – reassessments completed by all members of the team, now working on interdisciplinary care plan for AM

Profile

AM is an 84-year-old woman who has lived in a memory care facility for the last 3 years and has severe MNCD. AM is able to answer to her name but has decreased verbal generative fluency. She smiles and nods her head in greeting, but does not engage in conversations. She follows the housekeeping staff around during the day. Her family believes that AM enjoys watching cleaning when it is done well. They report similar behavior in AM's younger years; she liked keeping the house clean when her children were young. She also liked to cook, but hasn't done any cooking for the last 20 years.

Change in Condition

AM's behavior began to change about 3 weeks ago. She frequently becomes distressed, screaming at staff and chasing people who come into her room. These episodes occur on an almost daily basis, typically in the late afternoon. She takes several hours to calm down when she becomes upset. She has lost 17 pounds in the last 4 months. No precipitating factors or changes at the memory care unit have been identified. Her daughter's visit frequency is about the same.

Life factors influencing current condition

- Per family, AM would not have described herself as a religious person.
- Homemaker, kept a spotless house, was an excellent cook.

- Liked getting her nails done, has not been able to sit for this in the past 6 months.
- Loved to travel.
- Husband was an artist.
- One daughter is married with a grown child of her own, lives near the Memory Care Unit, and visits most days.

Assessments

Neuropsychiatric Inventory-Q form: score – severity 14, caregiver distress 18.

Aggression 3/4, depression 3/5, anxiety 3/5, irritability 2/3, eating 3/2

MSSE: score of 7 – not calm 1, screams 1, malnutrition 1, eating problem 1, invasive actions (CBG) 1, suffering according to medical opinion 1, suffering according to family 1

Domain

Goals of care/end-of-life issues: Now in a palliative care, comfort care track

AM perspective: "No pain" was the last conversation about this, which occurred approximately 2 years ago. She has not been able to verbally provide additional input, although she has been communicating distress with her behavior.

Daughter: Family supports a focus on comfort. They are unsure what might be causing AM's current outbursts.

Interdisciplinary team: Focus is on keeping AM comfortable and minimizing pain. Consideration is being given to current increase in distress and whether it is related to pain. Team is pondering if AM has started the transition to the end of life and estimates the trajectory over the next 1–2 months. MSSE suggests life expectancy of 6 months or less. Referral to hospice services is recommended to AM and her family.

Participant perspective	Issues	Plan	Discipline
"No pain" was the last conversation about this, 2 years ago	GOC/ palliative care philosophy of comfort	Patient to be kept comfortable and pain-free; if that becomes difficult, refer to hospice for more wrap-around care – now will increase medications and refer to hospice	PCP, RN, SW
"I want to be cremated" stated 5 years ago	Funeral plan	AM and her family have arrangement with XYZ Funeral Home. Copies of paperwork in chart at memory care, with daughter, and at PCP office	SW, housing director, daughter, PCP
Daughter reports "My mom is suffering"	NPS: Mini-Suffering State Exam Score 7/10	Problem solve as needed to support stable placement Provide caregiver assistance with developing interventions Continue to track MSSE, NPI-Q	MSW, RN

Participant perspective	Issues	Plan	Discipline
Screaming and pushing	NPS: NPI-Q score 14/18	Psychiatry collaborative consultation: recommends having daughter come at 3pm and lay down with her mother to see if "modeling how to rest" helps. Move AM away from the noise before it starts to increase around 3pm. Continue dementia-specific medications. Trial pain meds (low-dose opiate+bowel medications) while beginning behavioral interventions as she appears to be suffering greatly	PCP, consult with psychiatry
AM able to walk, able to eat finger-food	Functional status	Continues as expected. Support by walking regularly with AM, and provide food in line with her preferences	Staff at MCU, daughter, activity dir

Participant perspective	**Issues**	**Plan**	**Discipline**
Appears upset when medications are handed to her and when her CBG is checked	Medical: HTN DM	Discontinue all medications that are not being given for NPS Discontinue CBGs. Encourage fluids as elevated CBG can lead to dehydration	PCP, RN
Daughter speaking for AM: MCU meets her mother's needs	Living environment and safety	Continue MCU with added support from hospice staff	PCP, RN, MCU, hospice

After review of the care plan, all team members sign:
AM _________ Date ______ Dtr A ________ Date ______
SW_________ Date _____ RN __________ Date ______
Aide ________ Date ______ OT__________ Date ______
PCP ______ Date _____ Housekeeper_________ Date _____
MCU Dir ________ Date ____ Act Dir ________ Date _____

Outstanding actions:

SW and PCP will make hospice referral and send the first and current person-centered care plans. Hospice to consult with AM, Daughter, MCU staff, and rest of team.

Date of referral:________

Comments/Additions from AM or Dtr A:

____

____

Appendix B: Sample Care Plan Chapter 9

Background Information

Date of report: September 21, 2019 Client's name or initials: BN

Date of birth: April 10, 1940

Reason for care plan update: Regular reassessments completed by all members of the team, now working on interdisciplinary care plan for BN.

Profile

BN is a 79-year-old woman who has lived in assisted living facility for the last 3 years and has mild MNCD. BN is able to have conversations. She enjoys talking, reading, and playing cards. She loses track of conversations at times and has limited recall. Notes don't seem to help much.

- Roman Catholic background. Attends mass on Sundays.
- Librarian, loves to read, is in a book club at ALF.
- Likes getting her hair done.
- Loved to travel.
- Husband was a civil servant.
- No children. Niece lives in a distant state but calls BN once per month.

Neuropsychiatric Inventory-Q form: severity 2, caregiver distress 2

Anxiety 1/1, irritability 1/1

MSSE: 1/10 dialysis

BN's perceptions: Things seem good right now. Lots of minor medical issues, but living here has been good for me. I have a whole new group of friends. The food is pretty good too.

Domain: End-of-life issues – now in a palliative care, functional focus track

BN perspective: "As long as I can keep going and enjoy time with friends, life is good."

Other interdisciplinary team members – continue to support optimal quality of life. Life expectancy is less than 5 years. DNR is in place. If benefits of an intervention are less than risk over next 5 years, advise against them.

Participant perspective	Issues	Plan	Discipline
I don't want CPR; I saw that happen to my best friend, and it was awful	GOC: Focus on daily functioning palliative care philosophy	Encourage BN to be as active as possible; her "use it or lose it" attitude is lifelong	RN, ALF act dir, aides
"I want to be cremated" stated 5 years ago	Funeral plan	Copies of paperwork in chart, with daughter and at PCP office	Housing director, PCP
Denies suffering	Mini-Suffering State Exam Score 1/ 10	Problem solve as needed to support functioning Provide caregiver education regarding end of life as needed	MSW, RN
Some anxiety during dialysis	NPI-Q score 1/2	Encourage listening to music and watching distracting movies during dialysis. Discuss when it may be time to stop due to not supporting a good quality of life, and document those discussions	Kidney team, PCP

Domain: Cognition/functioning

BN perspective: "I lose track of some things, I need the staff help, life is good."

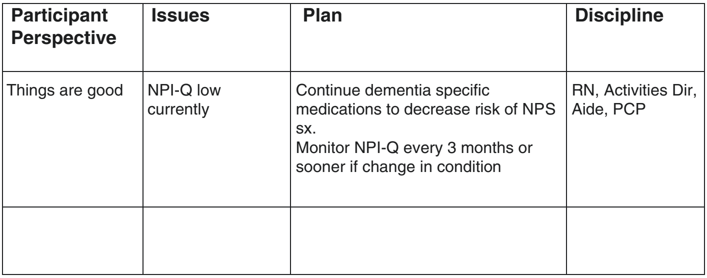
Other interdisciplinary team members – Allen cognitive level 4.6 mild-moderate functional impairment. Strengths are ability to scan the environment and utilize objects if they are visible.

Participant perspective	Issues	Plan	Discipline
I need reminders	Does not track dialysis days any longer, benefits from invitation to activities	Staff to come and get her for medical and dialysis appointments, invite to all activities, and keep track of her schedule for her	Aides, ALF RN, and manager to monitor

Domain: Emotional/neuropsychiatric symptoms

BN perspective: I get nervous sometimes. I am not depressed. I enjoy being as active as I can.

Other interdisciplinary team members – the emotional impact of dialysis is emerging as an area to attend to closely. At some point, if it causes too much distress, will need to discuss stopping dialysis.



Participant Perspective	Issues	Plan	Discipline
Things are good	NPI-Q low currently	Continue dementia specific medications to decrease risk of NPS sx. Monitor NPI-Q every 3 months or sooner if change in condition	RN, Activities Dir, Aide, PCP

Domain: Medical

BN perspective: I can tolerate dialysis for now. Maybe not for too much longer. Otherwise, I don't think I have medical problems.

Other interdisciplinary team members – continue much of current care. Frank conversation now with BN and her niece and the PCP about the future of stopping dialysis. Begin to plan for that. Send documentation of care plan to nephrologist and offer to have joint meeting with PCP, BN, and niece by phone with nephrologist.

Participant perspective	Issues	Plan	Discipline
7 years ago, completed	Advanced directive	Participant named niece her primary healthcare power of attorney, she does not have an alternate	PCP
"I get tired a lot"	End-stage renal disease on hemodialysis – secondary hyperparathyroidism and anemia CPAP at night History of low protein levels	Continue Sensipar and sevelamer Check labs prn Increase daily water intake Renal follow-up per schedule Lab draws/blood pressure checks left arm only Draw labs as ordered Hemodialysis three times a week Communicate with XXX Kidney Center to reschedule run when participant has missed run Make sure settings are correct every night and put away every morning Encourage compliance Replace respiratory care supplies per replacement schedule Renal diet: participant has been educated on renal diet guidelines Small portions of meals as she desires Nutrition supplement Weigh at ALF once a month, and send to PCP and nephrologist	PCP RN Care aide RN

Domain: Living environment/safety

BN perspective: I really like living here. I have friends and enjoy activities.

Other interdisciplinary team members – At the current time, BN's needs are being met well here. Continue to focus on maximizing ability to be as independent as possible.

Participant perspective	**Issues**	**Plan**	**Discipline**
I love to read	Active in book club	Continue to encourage to read, especially well-loved books BN is familiar with	Activity director
My eyes get tired when I read	Decreased visual acuity	Provide large print books and magnification device	Occupational therapist
I sometimes forget when book club is; I would hate to miss it	Decreased short-term memory	Provide environmental cues to remind BN of schedule; large digit clock with alarm Reminds 10 minutes before group starts	Occupational therapist; activity director

After review of the care plan, all team members sign:
BN _________ Date _______ Niece ________ Date _______
SW_________ Date _______RN __________ Date _______
Aide ________ Date ______ OT__________ Date ______
PCP _________ Date _____ Act Dir ________ Date _____
Housing Coordinator____________ Date _______

Outstanding actions:

Send copy of Person Centered Care Plan to Nephrologist office

Dr. _____________ Date_________

Comments/Additions from BN or Niece:

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