Caring for and Treating Individuals with Neurocognitive Disorders:
A Triangulation Approach for Neurocognitive Disorder Special Care Best Practices

February 2014
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Training Course Objectives

By the end of this course, the professional caregiver will:

- Familiarize self with local and federal care regulations
- Understand neurocognitive disorders and other neurobehavioral conditions such as Alzheimer's disease
- Realize Behavior as a form of Communication: We Need to Know the Language to be Effective and Compassionate
- Identify the Impact of the Physical Environment on Individuals with Neurocognitive Disorders
- Be familiar with Resident Centered Approaches to Caring for Individuals with Neurocognitive Disorders
- Recommend Therapeutic Approaches to Activities of Daily Living for Individual with Neurocognitive Disorders
- Elicit Purposeful Activity and Social Engagement between Individuals and their Caregivers
- Work with Families and Caregivers of Individuals Living with Neurocognitive Disorders in an effective manner
- Recognize and recommend strategies to respond to caregiver’s stress
- Prevent, recognize and respond to signs of neglect and or abuse of individuals with Neurocognitive Disorders
Section One: Regulations for Special Care Providers

Circular Letter: DHCQ – 14-5-615

TO: Nursing Home Administrators
FROM: Sherman Lohnes, Director, Division of Health Care Quality
       Paul DiNatale, Assistant Director, Division of Health Care Quality
SUBJECT: Guidelines for Dementia Special Care Unit Regulations
DATE: May 22, 2014

On February 28, 2014, the Department of Public Health amended its regulation for long term care facilities to include requirements for the care of residents with dementia. Under the amended regulation, a licensed facility or a unit thereof, that uses any word, term, phrase, or image, or suggests in any way, that it is capable of providing specialized care for residents with dementia, must comply with 105 CMR 150.022 through 150.029.

Training:

Under 105 CMR 150.025, all training required for relevant staff members must be in accordance with Department guidelines. Relevant staff members are defined as “…direct care workers, therapeutic activity directors and supervisors of direct care workers.”

Training conducted to meet the requirements of 105 CMR 150.024 must include, at a minimum, the following topics:

- A basic introduction to the foundations of Alzheimer’s and other related dementias;
- Training on communicating and connecting with residents with Alzheimer’s and other related dementias;
- Training on techniques and approaches to care of persons with Alzheimer’s and dementia;
- Training on person centered care;
- Training on understanding the needs of and working with the families;
- Training on the dietary needs of residents with Alzheimer’s and other related dementia;
• Training on the social needs and appropriate activities in the care of residents with Alzheimer’s and other related dementia;
• Recognizing and responding to caregiver stress; and,
• Preventing, recognizing, and responding to abuse and neglect of residents with Alzheimer’s and other related dementia.

Training conducted to meet the requirements of 105 CMR 150.024 must be at least partially interactive. The Department considers “partially interactive” to be training that does not consist of the presentation of information through reading or lecture alone. Since adult learning styles differ, training should be planned and conducted in a meaningful part with the use of interactive learning techniques such as interactive or experiential exercises, small group discussion or exercises, role play, and case study.

As a number of effective training programs have already been adopted by facilities including but not limited to the Alzheimer’s Association’s “Habilitation Therapy – Caring for People with Dementia”, Hand in Hand, and OASIS (augmented with additional training and focus related to Alzheimer’s and dementia care), DPH will not be requiring or excluding the use of any specific training program at this time. Facilities must ensure that the basic curriculum used incorporates at a minimum the above-mentioned topics.

As indicated in the regulation, training for facilities with a dementia special care unit was to have been completed by relevant staff members within three months of the promulgation of the regulation, and within six month for all other facilities. As the regulation required the development of guidelines by the Department, all facilities must provide training in accordance with the following timelines.

• All facilities with a dementia special care unit must have plans in place no later than June 21, 2014, (that is, within thirty days of the date of these guidelines) for the initial training of relevant staff members no later than the following dates:
  o Training for relevant staff members already providing care as of May 22, 2014, must be completed no later than August 22, 2014 (that is, within three months of the date of these guidelines);
  o Training for relevant staff members who begin providing care between May 22, 2014, and June 21, 2014, must be completed no later than August 22, 2014; and,
  o Training for relevant staff members who begin providing care on or after June 22, 2014, must be completed prior to their release from orientation in accordance with 105 CMR 150.024(B)(1).

• All other facilities must have plans in place for the initial training of relevant staff members no later than the following dates:
  o Training for relevant staff members already providing care as of May 22, 2014, must be completed no later than November 22, 2014, (that is, within six months of the date of these guidelines);
  o Training for relevant staff members who begin providing care between May 22, 2014, and August 27, 2014, must be completed no later than November 22, 2014; and,
Training for relevant staff members who begin providing care after August 27, 2014, must be completed prior to their release from orientation in accordance with 105 CMR 150.024(B)(1).

Facilities will not be required to retrain relevant staff members who have already completed eight hours of initial training that meets the requirements of 105 CMR 150.025(B)(2) or (3) and these guidelines. Facilities must have documentation that the initial training completed meet the requirements of the regulation and these guidelines. Relevant staff members who completed their training before January 1, 2014, must complete four hours of ongoing training during calendar year 2014 in accordance with 105 CMR 150.024(B)(4).

Physical Plant Requirements:

Facilities with a dementia special care unit must meet the physical plant requirements at 105 CMR 150.029. Facilities that do not meet these requirements may request additional time to implement necessary physical plant modifications, but must request a waiver by June 21, 2014, (that is, within thirty days of the date of these guidelines) using the standard waiver form. All waiver requests must include, in accordance with 105 CMR 153.031, information regarding what compensating features the facility has instituted, and documentation sufficient to demonstrate that granting a waiver will not affect the health or safety of residents or limit the facility's capacity to give adequate care.

Requests for a waiver of any of the physical plant requirement must specify how the facility will achieve compliance in a timely manner, but not later than February 28, 2015. Facilities must obtain plan approval prior to beginning any construction, renovations or alterations.

Any facility which anticipates that, due to unique circumstances, it will be impossible to meet the physical plant requirements by February 28, 2015, must provide sufficient documentation to the Department to support its request for a waiver beyond that date. As facilities are not required to have a dementia special care unit, the Department anticipates requests for a permanent waiver will be made in only the most extreme situations, and will be subject to thorough review by the Department before approval.

Disclosure Form:

Every nursing home that holds itself out to the public or advertises itself as having a dementia special care unit must submit a disclosure form (see attached) to the Department by June 21, 2014, (that is, within thirty days of the date of these guidelines) using the Health Care Facility Reporting System (HCFRS) under incident type “Dementia SCU Disclosure Form”, and then annually on March 1st, regardless of whether the information reported in the form has changed. A copy of each waiver requested by a facility must be attached to the disclosure form the facility submits to the Department and makes available in accordance with 105 CMR 150.028.

Facility questions regarding these regulations should be directed to the appropriate regional manager of the Department for that facility.
Before the changes were recommended to the Massachusetts CMR 150.000, The Affordable Care Act of 2010 in Section6121 required Center for Medicare and Medicaid (CMS) to ensure that nurses’ aides receive regular training in the care of residents with neurocognitive disorders and specific training on preventing abuse. In response to this legislation, CMS developed Hand In Hand: A Training Series for Nursing Homes.

Over the past couple of years, the Alzheimer’s Association put forth their response to this standard by creating Caring for People with Alzheimer’s disease: A Habilitation Training Curriculum.

The training presented herein, while incorporating many of the themes of the other trainings, has been developed for the professional caregiver. Sherlyn L. Fenton, OTD

Take test now for Section One
Section Two: Background to Neurocognitive Disorders

Neurocognitive disorders is an overall term that describes a wide range of symptoms associated with a decline in memory and cognition severe enough to impair an individual’s ability to perform activities of daily living. Neurocognitive disorders are often incorrectly referred to as "senility" or "senile dementia," which reflects the formerly widespread but incorrect belief that serious mental decline is a normal part of aging.

Different types of neurocognitive disorders are associated with particular types of brain cell damage in particular regions of the brain. For example, in Alzheimer's disease, high levels of certain proteins inside and outside brain cells make it hard for brain cells to stay healthy and to communicate with each other. The brain region called the hippocampus is the center of learning and memory in the brain, and the brain cells in this region are often the first to be damaged. That's why memory loss is often one of the earliest symptoms of Alzheimer's disease.

While most changes in the brain that cause neurocognitive disorders are permanent and worsen over time, thinking and memory problems caused by depression, medication side effects, excess use of alcohol, thyroid problems and vitamin deficiencies may improve when the condition is treated or addressed.

Many neurocognitive disorders are progressive, meaning symptoms start out slowly and gradually get worse. Professional evaluation may detect a treatable condition. And even if symptoms suggest neurocognitive disorders, early diagnosis allows a person to get the maximum benefit from available treatments and provides the individual an opportunity to volunteer for clinical trials or studies. Early detection also provides time to plan for the future.

Risk Factors of Neurocognitive Disorders

- Advanced age
- Mild cognitive impairment
- Cardiovascular disease
- Genetics: family history of dementia, Parkinson's disease, cardiovascular disease, stroke, presence of ApoE4 allele on chromosome 19
- Environment: head injury, alcohol use

Neurocognitive disorders are caused by damage to brain cells. This damage interferes with the ability of brain cells to communicate with each other. When brain cells cannot communicate normally, thinking, behavior and feelings can be affected. Some risk factors for neurocognitive disorders, such as age and genetics, cannot be changed. But researchers continue to explore the impact of other risk factors on brain health and prevention of neurocognitive disorders. Some of the most active areas of research in risk reduction and prevention include cardiovascular factors, physical fitness, and diet.

Cardiovascular risk factors: Your brain is nourished by one of your body's richest networks of blood vessels. Anything that damages blood vessels anywhere in your body can also damage blood vessels in your brain, depriving brain cells of vital food and oxygen. Blood vessel changes in the brain are linked to vascular
dementia. They often are present along with changes caused by other types of neurocognitive disorders, including Alzheimer's disease and dementia with Lewy bodies. These changes may act together to cause quicker decline or make impairments more severe. You can help protect your brain with some of the same strategies that protect your heart. As with a healthy heart, individuals are encouraged to not smoke; maintain healthy blood pressure, cholesterol and blood sugar within recommended limits; and maintain a steady, healthy weight.

**Physical exercise:** Regular physical exercise may help lower the risk of some types of neurocognitive disorders. Evidence suggests exercise may directly benefit brain cells by increasing blood and oxygen flow to the brain.

**Diet:** What you eat may have its greatest impact on brain health through its effect on heart health. The best current evidence suggests that heart-healthy eating patterns may help protect the brain. A diet should include relatively little red meat and emphasizes whole grains, fruits and vegetables, fish and shellfish, nuts, olive oil and other healthy fats.

**Components of Mental Status Functioning**

The brain has many distinct regions, each of which is responsible for different functions (for example, memory, judgment and movement). When cells in a particular region are damaged, that region cannot carry out its functions in a normal way. People with neurocognitive disorders may have problems with short-term memory, keeping track of a purse or wallet, paying bills, planning and preparing meals, remembering appointments or traveling out of the neighborhood. While symptoms of neurocognitive disorders can vary greatly, at least two of the following core mental functions must be significantly impaired to be considered neurocognitive disorders:

- Memory
- Communication and language
- Ability to focus and pay attention
- Reasoning and judgment
- Visual perception
- Motor function

The prevalence of neurocognitive disorders is distressing. Neurocognitive disorders affect about 5% of individuals 65 and older. Four to five million Americans have neurocognitive disorders. Fourteen million are projected to have neurocognitive disorders by the year 2040. Global prevalence of neurocognitive disorders is about 24.3 million, with 6 million new cases every year. The goals of professional caregivers must be two-fold: 1) Early recognition of neurocognitive disorder related illnesses and 2) Appropriate management strategies to care for individuals with neurocognitive disorders.

The rapid growth of the aging population is associated with an increase in the prevalence of progressive neurocognitive disorders. It is imperative that a differential diagnosis be ascertained early in the course of cognitive impairment and that the individual is closely monitored for coexisting morbidities. Professional healthcare practitioners have a central role in assessment and management of individuals with progressive neurocognitive disorders.

Ultimately, the path to effective new treatments for neurocognitive disorders is through increased research funding and increased participation in clinical studies. Right now, at least 50,000 volunteers are urgently needed to participate in more than 100 actively enrolling clinical studies and trials about Alzheimer's and related neurocognitive disorders.
Understanding Alzheimer's and other Types of Neurocognitive Disorders

Alzheimer's disease is one type of neurocognitive disorder which accounts for 60 to 80 percent of neurocognitive disorder-classified cases. Vascular dementia, which occurs after a stroke, is the second most common neurocognitive disorders type. But there are many other conditions that can cause symptoms of neurocognitive disorders, including some that are reversible, such as thyroid problems and vitamin deficiencies.

Alzheimer's disease is a progressive, neurodegenerative disease characterized in the brain by abnormal clumps (amyloid plaques) and tangled bundles of fibers (neurofibrillary tangles) composed of misplaced proteins. Age is the most important risk factor for Alzheimer's disease. The number of people with the disease doubles every 5 years beyond age 65. Three genes have been discovered that cause early onset (or family) Alzheimer's. Other genetic mutations that cause excessive accumulation of amyloid protein are associated with age-related (sporadic) Alzheimer's.

Alzheimer's disease is characterized by the development of multiple cognitive deficits manifested by:

- Memory impairment (impaired ability to learn new information or to recall previously learned information)
- And one (or more) of the following cognitive disturbances:
  - Deterioration of language may be manifested by difficulty producing the names of individuals and objects (aphasia)
  - An impaired ability to carry out motor activities (such as combing their hair) despite intact motor abilities, sensory function and comprehension of the required task (apraxia)
  - A failure to recognize or identify objects despite intact sensory function (agnosia)
  - A disturbance in executive functioning (e.g., planning, organizing, sequencing, abstracting)

The cognitive deficits above each cause significant impairment in social or occupational functioning and represent a significant decline from a previous level of functioning. The course is characterized by gradual onset and continuing cognitive decline. The deficits do not occur exclusively during the course of a delirium, a reversible decline in cognitive functioning.

Symptoms of Alzheimer's disease include memory loss, language deterioration, and impaired ability to mentally manipulate visual information, poor judgment, confusion, restlessness, and mood swings. Eventually Alzheimer's destroys cognition, personality, and the ability to function. The early symptoms of Alzheimer's disease, which include forgetfulness and loss of concentration, are often missed because they resemble natural signs of aging.

Memory loss is the most well-known problem associated with Alzheimer’s disease and other neurocognitive disorders. However, the decline in the ability of the brain to process visual information is also profound. Such visual changes are all but unknown to both the general public, as well as too many professional caregivers.

Scientists do not yet fully understand what causes Alzheimer's disease. There probably is not one single cause, but several factors that affect each person differently.
Family history is another risk factor. Scientists believe that genetics may play a role in many Alzheimer's
disease cases. For example, familial Alzheimer's disease, a rare form of Alzheimer's disease that usually occurs
between the ages of 30 and 60, can be inherited. One risk factor for this type of Alzheimer's disease is a
protein called apolipoprotein E (apoE). Everyone has apoE, which helps carry cholesterol in the blood.
The apoE gene has three forms. One seems to protect a person from Alzheimer's disease, and another seems
to make a person more likely to develop the disease. However, in the more common form of Alzheimer's
disease, which occurs later in life, no obvious familial pattern has been identified. Other genes that increase
the risk of Alzheimer's disease or that protect against Alzheimer's disease probably remain to be discovered.
Scientists still need to learn a lot more about what causes Alzheimer's disease. In addition to genetics and
apoE, they are studying education, diet, environment, and viruses to learn what role they might play in the
development of this disease.

Differential Diagnoses and Alzheimer's disease

Today, the only definite way to diagnose Alzheimer's disease is to find out whether there are plaques and
tangles in brain tissue. To look at brain tissue, doctors must wait until they do an autopsy, which is an
examination of the body done after a person dies. Therefore, doctors must make a diagnosis of "possible" or
"probable" Alzheimer's disease. In a diagnosis of Alzheimer's disease, the cognitive deficits described above
are not due to any of the following:

- Substance-induced conditions
- Other central nervous system conditions that cause progressive deficits in memory and cognition
  (e.g., cerebrovascular disease, Parkinson's disease, Huntington's disease, subdural hematoma, normal-
  pressure hydrocephalus, brain tumor)
- Systemic conditions that are known to cause neurocognitive disorders (e.g., hypothyroidism, vitamin
  B-12 or folic acid deficiency, niacin deficiency, hypercalcemia, neurosyphilis, HIV infection)

Information from the medical history and test results help the doctor rule out other possible causes of the
person's symptoms. For example, thyroid problems, drug reactions, depression, brain tumors, and blood
vessel disease in the brain can cause Alzheimer's disease-like symptoms. Some of these other conditions can
be treated successfully. The course of Alzheimer's disease varies from person to person. On average,
Alzheimer's disease patients live from 8 to 10 years after they are diagnosed, though the disease can last for as
many as 20 years.

An early, accurate diagnosis of Alzheimer's disease is imperative because it offers the best chance to treat the symptoms of the disease.
Moreover, it can help individuals and their families plan for the future and discuss care preferences while the patient can take part in making
decisions.

Case Study 2 - Alzheimer's patient, Don Hayen
Section Three: Stages of Neurocognitive Disorders

Dr. Barry Reisberg, Clinical Director of New York University's Aging and Dementia Research Center, summarizes the seven major clinical stages of Alzheimer's disease. Dr. Reisberg has developed the “Global Deterioration Scale” which is now used in many diagnoses and care settings as the rating scale.

Stage 1: Normal

Individuals at any age with no signs or symptoms of cognitive, behavioral and functional decline are considered stage 1 - normal.

Stage 2: Normal aged forgetfulness

More than half of the population over the age of 65 report cognitive, behavioral and/or functional difficulties. Elderly persons with these experiences believe they can no longer recall names or the places they have placed items as well as they could 5 or 10 years previously. Subjective reporting also includes difficulties in concentration and in word finding when speaking becoming common.

Various terms have been suggested for this condition, but normal aged forgetfulness is probably the most satisfactory terminology. These symptoms which, by definition, are not notable to intimates or other external observers of the person with normal aged forgetfulness are generally benign. However, there is some recent evidence that persons with these symptoms do decline at greater rates than similarly aged persons and similarly healthy persons who are free of subjective complaints.

Stage 3: Mild Cognitive Impairment

Persons at this stage manifest deficits which are subtle, but which are noted by persons who are closely associated with the stage 3 subjects. The subtle deficits may manifest in diverse ways. For example, the person with mild cognitive impairment (MCI) may noticeably repeat questions. The capacity to perform executive functions also becomes compromised. Commonly, for persons who are still working, job performance may decline. For those who must master new job skills, decrements in these capacities may become evident. For example, the MCI subject may be unable to master new computer skills. MCI subjects who are not employed, but who plan complex social events, such as dinner parties, may manifest declines in their ability to organize such events.

Other MCI subjects may manifest concentration deficits. Many persons with these symptoms begin to experience anxiety, which may be overtly evident. A majority of persons with stage 3 symptoms, overt decline will occur, and clear symptoms of dementia will manifest over intervals of approximately 2 to 4 years. In persons who are not called upon to perform complex occupational and/or social tasks, symptoms in this stage may not become evident to family members or friends of the MCI patient. Even when symptoms do become noticeable, MCI subjects are commonly midway or near the end of this stage before concerns result in clinical consultation.

Management of persons in this stage includes counseling regarding the desirability of continuing in a complex and demanding occupational role. Sometimes, a 'strategic withdrawal' in the form of retirement, may alleviate psychological stress and reduce both subjective and overtly apparent anxiety.
Stage 4: Mild Dementia

The diagnosis of Alzheimer's disease (AD) can be made with considerable accuracy in this stage. Symptoms of impairment become evident in this stage. For example, seemingly major recent events may, or may not be remembered. Similarly, overt mistakes in recalling the day of the week, month or season of the year may occur. Patients at this stage can still generally recall their correct current address. They can also generally correctly recall the weather conditions outside and very important current events, such as the name of a prominent head of state.

Despite the overt deficits in cognition, persons at this stage can still potentially survive independently in community settings. However, functional capacities become compromised in the performance of IADLs. For example, there is a decreased capacity to manage personal finances. For the stage 4 patients who are living independently, this may become evident in the form of difficulties in paying rent and other bills. A spouse may note difficulties in writing the correct date and the correct amount in paying checks. The ability to independently market for groceries also becomes compromised in this stage. Persons who previously prepared meals for family members and/or guests begin to manifest decreased performance in these skills. Similarly, the ability to order food from a menu in a restaurant setting begins to be compromised. Frequently, this is apparent when the patient hands the menu to their companion and saying 'you order'.

The dominant mood at this stage is frequently what psychiatrists term a flattening of affect and withdrawal. In other words, the patient often seems less emotionally responsive than previously. This absence of emotional responsivity is probably intimately related to the patient's denial of their deficit, which is often also notable at this stage. Although the patient is aware of their deficits, this awareness of decreased intellectual capacity is too painful for most persons and, hence, the psychological defense mechanism known as denial, whereby the patient seeks to hide their deficit, even from themselves where possible, becomes operative. Consequently, the patient withdraws from participation in activities such as conversations.

In the absence of complicating medical pathology, the diagnosis of AD can be made with considerable certainty from the beginning of this stage. Studies indicate that the duration of this stage of mild AD has a mean of approximately 2 years.

Stage 5: Moderate Dementia

The characteristic functional change in this stage is emerging deficits in basic activities of daily living (ADL). The individual with Moderate AD has difficulty in their ability to choose proper clothing to wear for the weather conditions and/or for the daily circumstances. Some patients begin to wear the same clothing day after day unless reminded to change. Caregivers need to counsel regarding the choice of clothing.

Cognitively, persons at this stage frequently cannot recall such major events and aspects of their current lives as the name of the current president, the weather conditions of the day, or their correct current address. Characteristically, some of these important aspects of current life are recalled, but not others. Also, the information is loosely held, so, for example, the patient may recall their correct address on certain occasions, but not others.

Remote memory also suffers to the extent that persons may not recall the names of some of the schools which they attended for many years, and from which they graduated. Orientation may be compromised to the extent that the correct year may not be recalled. Calculation deficits are of such magnitude that an educated person has difficulty counting backward from 20 by 2s.
Patients can no longer manage on their own in the community. If they are seemingly alone in the community then there is generally someone who is assisting in providing adequate and proper food, as well as assuring that the rent and utilities are paid and the patient's finances are taken care of. For those who are not properly watched and/or supervised, predatory strangers may become a problem. Very common reactions for persons at this stage who are not given adequate support are behavioral problems such as anger and suspiciousness.

Functionally, persons at this stage have incipient difficulties with basic activities of daily life. The characteristic deficit of this type is decreased ability to independently choose proper clothing. This stage lasts an average of approximately 1.5 years.

**Stage 6: Moderately Severe Dementia**

During this stage, the ability to perform basic activities of daily life becomes compromised. Functionally, five successive sub stages are identifiable. Initially, in stage 6a, patients, in addition to having lost the ability to choose their clothing without assistance, begin to require assistance in putting on their clothing properly. Unless supervised, patients may put their clothing on backward, they may have difficulty putting their arm in the correct sleeve, or they may dress themselves in the wrong sequence.

Throughout the stage of moderately severe Alzheimer's disease, the cognitive deficits are of sufficient degree as to interfere with the ability to carry out basic activities of daily life. Generally, the earliest such deficit noted in this stage is decreased ability to put on clothing correctly without assistance. The total duration of the stage of moderately severe AD (stage 6a through 6e) is approximately 2.5 years.

For example, patients may layer their daytime clothes on over their night clothes. At approximately the same point in the evolution of AD, patients lose the ability to bathe without assistance (stage 6b). Characteristically, the earliest and most common impairment in bathing is difficulty adjusting the temperature of the bath water. Initially, once the caregiver adjusts the temperature of the bath water, the patient can still usually bathe independently. As this stage advances additional deficits in bathing independently as well as in dressing independently occur. In this 6b sub stage, patients generally develop deficits in other modalities of daily hygiene such as properly brushing their teeth independently.

With the further evolution of AD, patients lose the ability to manage the mechanics of toileting correctly (stage 6c). Unless supervised, patients may place the toilet tissue in the wrong place. Many patients will forget to flush the toilet properly. As the disease progresses in this stage, patients subsequently become incontinent. Generally, urinary incontinence occurs first (stage 6d), then fecal incontinence occurs (stage 6e). The incontinence can be treated, or even initially prevented entirely in many cases, by frequent toileting. Strategies for managing incontinence may include absorbent undergarments and appropriate bedding.

In this sixth stage cognitive deficits are generally so severe that persons will display little or no knowledge when asked regarding such major aspects of their current life circumstances as their current address or the weather conditions of the day. At stage six, the patient's cognitive deficits are generally so significant that the patient may at times confuse their spouse with their parent or be uncertain of loved ones. At the end of this stage, speech ability visibly breaks down.

Persons at this sixth stage will most often not be able to recall the names of any of the schools which they attended. They may, or may not, recall such basic life events as the names of their parents, their former occupation and the country in which they were born. They still have some awareness of their own names; however, patients in this stage begin to confuse their spouse with their deceased parent and otherwise mistake the identity of persons, even close family members, in their own environment. Calculation ability is frequently so severely compromised at this stage that even well-educated patients had difficulty counting backward consecutively from 10 by 1s.
Emotional changes generally become most overt and disturbing in this sixth stage of AD. Although these emotional changes may, in part, have a neurochemical basis, they are also clearly related to the patient’s psychological reaction to their circumstances. For example, because of their cognitive deficits, patients can no longer channel their energies into productive activities. Consequently, unless appropriate direction is provided, patients begin to fidget, to pace, to move objects around and place items where they may not belong, or to manifest other forms of purposeless or inappropriate activities. Because of the patient’s fear, frustration and shame regarding their circumstances, as well as other factors, patients frequently develop verbal outbursts, and threatening, or even violent, behavior may occur. Because patients can no longer survive independently, they commonly develop a fear of being left alone. Treatment of these and other behavioral and psychological symptoms which occur at this stage, as well as at other stages of AD, involves counseling regarding appropriate activities and the psychological impact of the illness upon the patient, as well as the caregivers.

The mean duration of this sixth stage of AD is approximately 2.3 years. As this stage comes to an end, the patient, who is doubly incontinent and needs assistance with dressing and bathing, begins to manifest overt breakdown in the ability to articulate speech: stuttering, buzzwords, and/or an increased lack of speech, become obvious.

**Stage 7: Severe Dementia**

At this stage, AD patients require continuous assistance with basic activities of daily life for survival. Six consecutive functional sub stages can be identified over the course of this final seventh stage. Early in this stage, speech has become so circumscribed, as to be limited to approximately a half dozen intelligible words or fewer in the course of an intensive contact and attempt at an interview with numerous questions (stage 7a). As this stage progresses, speech becomes even more limited to, at most, a single intelligible word (stage 7b). Once speech is lost, the ability to ambulate independently (without assistance), is invariably lost (stage 7c). However, ambulatory ability is readily compromised at the end of the sixth stage and in the early portion of the seventh stage by associated physical disability, poor care, medication side-effects or other factors. Conversely, outstanding care provided in the early seventh stage, and particularly in stage 7b, can postpone the onset of loss of ambulation, potentially for many years. However, under ordinary circumstances, stage 7a has a mean duration of approximately 1 year, and stage 7b has a mean duration of approximately 1.5 years.

Each sub stage of this final seventh stage lasts an average of 1-1.5 years.

In patients who remain alive, stage 7c lasts approximately 1 year, after which patients lose the ability not only to ambulate independently, but also to sit up independently (stage 7d). At this point in the evolution of AD, patients will fall over when seated unless there are arm rests to hold the patient up in the chair.

This 7d sub stage lasts approximately 1 year. Patients who survive subsequently lose the ability to smile (stage 7e). At this sub stage only grimacing facial movements are observed in place of smiles, this 7e sub stage lasts a mean of approximately 1.5 years. It is followed in survivors, by a final 7f sub stage, in which AD patients additionally lose the ability to hold up their head independently.

With appropriate care and life support, patients can survive in this final sub stage of AD for a period of years.

With the advent of the seventh stage of AD, certain physical and neurological changes become increasingly evident. One of these changes is physical rigidity. In many patients, this rigidity appears to be a precursor to the appearance of overt physical deformities in the form of contractures. Contractures are irreversible deformities which prevent the passive or active range of motion of joints. In the early seventh stage (7a and 7b), approximately 40% of AD patients manifest these deformities. Later in the seventh stage, in immobile patients (from stage 7d to 7f), nearly all AD patients manifest contractures in multiple extremities and joints.
Neurological reflex changes also become evident in the stage 7 AD patient. Particularly notable is the emergence of so-called 'infantile', 'primitive' or 'developmental' reflexes which are present in the infant but which disappear in the toddler. These reflexes, including the grasp reflex, sucking reflex, and the Babinski plantar extensor reflex, generally begin to re-emerge in the latter part of the sixth stage and are usually present in the stage 7 AD patient. Because of the much greater physical size and strength of the AD patient in comparison with an infant, these reflexes can be very strong and can impact both positively and negatively on the care provided to the AD patient. AD patients commonly die during the course of the seventh stage. The mean point of demise is when patients lose the ability to ambulate and to sit up independently (stages 7c and 7d).

In individuals with end stage AD and good care, the most frequent cause of death is pneumonia. Aspiration is one common cause of terminal pneumonia. Another common cause of demise in AD is infected decubiti ulcerations. AD patients in the seventh stage appear to be more vulnerable to all of the common causes of mortality in the elderly including stroke, heart disease and cancer. Some patients in this final stage appear to succumb to no identifiable condition other than AD.

Section Four: Determining an Individual’s Mental Status
Thru Evidence-Based Assessments

As you have learned, early diagnosis is essential in ensuring a good quality of life for an individual and their family when neurocognitive disorders are suspected. With this said, Fletcher reminds healthcare professionals that a mental status assessment must be conducted with the individual’s consent. *Completing a mental status assessment against the patient's will is legally considered assault with battery.* Therefore, it is important to attain the patient's or the patient’s responsible agent permission or to clearly document that a mental status evaluation is being done without approval due to emergency circumstances (Kathleen Fletcher, RN, MSN, APRN-BC, GNP, FAAN offers a Geriatric Nursing Protocol: Recognition and Management of Dementia which is evidence-based and was updated August 2012).

Doctors diagnose Alzheimer's and other types of neurocognitive disorders based on a careful medical history, a physical examination, laboratory tests, changes in cognition, ADL function and behavior. Through these factors, physicians can determine that a person has neurocognitive disorders with a high level of certainty, however; it’s harder to determine the exact type of neurocognitive disorder because the symptoms and brain changes of different neurocognitive disorders can overlap. In some cases, a doctor may diagnose "neurocognitive disorder" and not specify a type.

Definitions/Distinctions

- Neurocognitive disorders are a clinical syndrome of cognitive deficits that involves both memory impairments and a disturbance in at least one other area of cognition such as aphasia, apraxia, agnosia, and disturbance in executive functioning.
- In addition to disruptions in cognition, neurocognitive disorders are commonly associated with changes in function and behavior.
- The most common forms of progressive neurocognitive disorders are Alzheimer's disease (dementia), vascular dementia, and dementia with Lewy bodies; the pathophysiology for each is poorly understood.
- Differential diagnosis of neurocognitive disorder conditions is complicated by the fact that comorbidities exist.

Parameters of Assessment

Clinicians are advised to be alert for cognitive and functional decline in older adults to detect neurocognitive disorders and dementia-like signs in their early stages. Assessment domains include cognitive, functional, behavioral, physical, caregiver, and environment.

Cognitive Parameters (Order of screening/assessment is specific)

1. Orientation: person, place, time
2. Memory: ability to register, retain, recall information
3. Attention: ability to attend and concentrate on stimuli
4. Thinking: ability to organize and communicate ideas
5. Language: ability to receive and express a message
6. Praxis: ability to direct and coordinate movements
7. Executive function: ability to abstract, plan, sequence, and use feedback to guide performance
Mental Status Screening Tools

- Mini-Mental State Examination (MMSE) is the most commonly used test to assess progressive cognitive change. On average, the MMSE declines 3 points per year in those with neurocognitive disorders. The MMSE is copyrighted and a comparable tool called the St. Louis Medical Status (SLUMS) Examination is in the public domain.
- Clock Drawing Test (CDT) is a useful measure of cognitive function that correlates with executive-control functions.
- Mini-Cognitive (Mini-Cog) combines the Clock Drawing Test with the three-word recall.
- Montreal Cognitive Assessment (MoCA) was designed as a rapid screening instrument for mild cognitive dysfunction. It assesses different cognitive domains: attention and concentration, executive functions, memory, language, visuoconstructional skills, conceptual thinking, calculations and orientation.

Before beginning, get consent!

Avoiding questions requiring a “Yes / No” answer is recommended. Assessments beginning with open-ended questions are preferred in order to put the patient at ease and to observe the patient's thought processes. Begin with questions such as "What brings you here today?" or "Tell me about yourself." These types of questions elicit responses that provide the basis of the interview. Throughout the session look for nonverbal cues from patients. As they speak, note if they are averting their eyes, fidgeting, playing with their keys, or bouncing their leg repeatedly. Note your full experience for both verbal and non-verbal responses.

As interactions progress with an individual with neurocognitive disorders, ask more specific questions in order to obtain specific information needed to complete the assessment. At this point during the initial sessions, a detailed patient history should be taken. The patient should begin with identifying the patient's chief complaint and reason for the assessment. This also is where all history of illness is recorded, including psychiatric history, medical history, surgical history, occupational history and medications and allergies.

Additionally, listing any significant family history is important while obtaining a complete social history. Ask if the patient has a home and what type of home. Also ask if the patient has a family, and, if so, if the patient lives with them. Vital to the recording of a patient's social history is any information that may aid caregivers in making accommodations for the patient when necessary. Try to get a sense of the individual's home environment and if there exists any barriers to discharge planning. This information can be very useful later, when determining treatment approaches. Following completion of the patient's history, perform the MMSE or SLUMS in order to test specific areas of the patient's spheres of consciousness.

The patient's sensorium and cognition are examined, most commonly using the Mini-Mental State Examination (MMSE). The clinician should ask patients if they know the current date and their current location to determine their level of orientation. Patients' concentration is tested by spelling the word "world" forward and backward. Reading and writing are evaluated, as is visuospatial ability. To examine patients'
abstract thought process, have them identify similarities between 2 objects and give the meaning of proverbs, such as "Don't cry over spilled milk."

Every patient interview affords the health care professional an invaluable opportunity to provide patient education. This time can be optimized to discuss such patient issues as medication compliance, ADL status, the benefits and risks of participation and other discipline-specific topics. Never underestimate providing needed education to patients.

The time it takes to complete the initial interview may vary. Professionals should not feel rushed to complete the session in a specific time frame. All patients require their own pace and should not be made to feel they are being timed. Once the history and Mental Status Screening are complete, documenting this event accurately and efficiently is important. If the individual’s status remains unclear, the patient should be referred for more extensive screening and neuropsychological testing, which might provide more direction and support for the patient and the caregivers. An interdisciplinary approach to an individual's assessment and care can create a more cohesive outcome with comprehensive care approaches.

**Functional Assessment**
1. Tests that assess functional limitations such as the Physical Self-Maintenance Scale (PSMS) and the Functional Activities Questionnaire (FAQ) can detect neurocognitive disorders. They are also useful in monitoring the progression of functional decline.

2. The severity of disease progression in neurocognitive disorders can be demonstrated by performance decline in activities of daily living (ADL) and instrumental activities of daily living (IADL) tasks and is closely correlated with mental-status scores.

**Behavioral Assessment**
1. Assess and monitor for behavioral changes; in particular, the presence of agitation, aggression, anxiety, disinhibitions, delusions, and hallucinations.

2. Evaluate for depression because it commonly coexists in individuals with neurocognitive disorders. The Geriatric Depression Scale (GDS) is a good screening tool.

**Physical Assessment**
1. A comprehensive physical examination with a focus on the neurological and cardiovascular system is indicated in individuals with neurocognitive disorders to identify the potential cause and/or the existence of a reversible form of cognitive impairment. A thorough evaluation of all prescribed, over-the-counter, homeopathic, herbal, and nutritional products taken is done to determine the potential impact on cognitive status.

2. Laboratory tests are valuable in differentiating irreversible from reversible forms of neurocognitive disorders. Structural neuroimaging with noncontrast computed tomography (CT) or magnetic resonance imaging (MRI) scans are appropriate in the routine initial evaluation of patients with neurocognitive disorders.
Section Five: Getting to Know and Understand the Individual with Neurocognitive disorders

How well do those closest in our own lives know us? Do they know our favorite songs and our food preferences? Do they know what we like to wear and what social activities make us feel fulfilled?

Although it is said that we all put our pants on one leg at a time, one's ADL habits and preferences are very personal and often vary in their frequency, duration, and approaches. As any new couple just moving in together may realize, how one manages a tube of toothpaste can be very individualized!

As caregivers, we know how an individual with a neurocognitive disorder spent their working hours and years. Were they happy with their job and do they identify themselves by their occupation? Does their life’s profession dictate their sleep wake patterns? Are they used to getting up early or staying up late? Did their job have an influence on their health?

When these individuals were not working, what were their interests and hobbies? Did they enjoy reading alone in a quiet place or would we have found them in the center of a crowd yelling for their race horse to come in first? When we take the time to get to know the individuals we care for, it is then that we can focus on resident centered care. More and more case studies are documenting the positive effects of "personalized" music in our residents’ lives. This does not mean simply having sound on in the background. It is about exploring the songs that the individual used to enjoy and creating a music list that is specific to the individual with a neurocognitive disorder. Although the concert and application of music therapy is not new, it certainly is going "viral" through social media networks to inform caregivers of the positive outcomes of this personalized approach.

Take a moment to watch Henry’s Story. Ctrl+click to follow link:

Case Study 3 - The Therapeutic Benefits of Personalized Music
Behavior as Communication: Understanding and Responding
Agitation and Alzheimer’s
As you have learned in Section three, stage six of AD is often met with new challenges for the individual with AD and the caregiver. Cognitive and emotional changes may result in behavioral outbursts that may seem difficult to understand. The best approach by the caregiver is to keep things simple and soft, ask questions that only require yes or no answers and offer fewer choices. Please view Frank’s video to see how Doreen’s different approaches make a difference.

Case Study 4 - Dementia with Agitation

Hallucinations and Alzheimer’s
As the disease progresses, a person with neurocognitive disorders may experience hallucinations and/or delusions. **Hallucinations** are when the person sees, hears, smells, tastes, or feels something that is not there. **Delusions** are false beliefs that the person cannot be persuade against.

- Sometimes hallucinations and delusions are a sign of a physical illness. Keep track of what the person is experiencing and discuss it with the doctor.
- Avoid arguing with the person about what he or she sees or hears. Try to respond to the feelings he or she is expressing, and provide reassurance and comfort.
- Try to distract the person to another topic or activity. Sometimes moving to another room or going outside for a walk may help.
- Turn off the television set when violent or disturbing programs are on. The person with neurocognitive disorders may not be able to distinguish television programming from reality.
- Make sure the person is safe and does not have access to anything he or she could use to harm themselves or anyone in their vicinity.
**Wandering and Alzheimer’s**

Keeping the individual with neurocognitive disorders safe is one of the most important aspects of caregiving. Some people with neurocognitive disorders have a tendency to wander away from their home and their caregiver(s). Knowing what to do to limit wandering can protect a person from becoming lost and experiencing harm. In skilled nursing communities, wandering is often referred to as elopement. It is essential that caregivers familiarize themselves with the policies and procedures of their specific facility to know how to respond to an elopement.

- Make sure that the person carries some kind of identification or wears a medical bracelet. Consider enrolling the person in the Alzheimer’s Association Safe Return program if the program is available in your area. If he or she gets lost and is unable to communicate adequately, identification will alert others to the person’s medical condition. Notify neighbors and local authorities in advance that the person has a tendency to wander.

- Maintaining a recent photograph or videotape of the person with neurocognitive disorders to assist police if the person wanders off.

- Securing doors by considering a keyed lock out of the individual’s line of vision. If the person can open a lock because it is familiar, a new latch or lock may help. Remember, people with Alzheimer’s can read so posting a door code is often ineffective!

- Be sure to secure or put away anything that could cause danger, both inside and outside the house.

**The Impact of the Physical Environment**

Individuals with neurocognitive disorders are able to function better with less confusion and distraction. Their environments need to be free of clutter in order for them to be as independent as possible. Building in success by keeping things simple allows the individual to feel more self-sufficient and improves their self-confidence.

While awareness must be heightened and approaches amended as the disease progresses, simple changes to the neurocognitive disorders patient’s environment can make a real difference in their safety and ability to function more independently thus improving their quality of life. Understanding what isn’t working correctly in the individual’s brain is imperative to applying appropriate care interventions.
Section Six: Communication Skills: We Need to Know the Language

Trying to communicate with a person who has neurocognitive disorders can be a challenge. Both understanding and being understood may be difficult. We must help them by altering how we communicate with them.

- **Approach calmly, from the front and, with a smile**
  Patients are easily startled; approaching from behind may scare them, watch non-verbal expressions.

- **Start contact with a gentle touch**
  This gets the patients attention and shows that you care and are not a threat. Remember: some people do not like to be touched and you must be aware of who these people are.

- **Establish eye contact**
  Maintain eye contact while you are talking to them to hold their attention and gain their trust.

- **Speak to the patient as one adult to another**
  Although some of their actions and reactions may be very similar to what a child does—they are still adults and should be treated as such. Never say things like “that’s a good boy,” or “you’re so cute,” or speak in a childish tone of voice.

- **Speak in a calm tone of voice**
  How you say something may be more important than what you say. Patients understand tone of voice and emotions easier than words.

- **Speak at a slower pace and allow time for the patient to respond**
  Speaking slowly gives patients more time to process and understand what the words mean and helps to keep them from becoming overwhelmed. Alzheimer’s disease slows down the time it takes to process information. You may think the patient is ignoring you when they are really just trying to figure out what you are saying.

- **Use as few words as possible**
  Break instructions into small parts. Instead of saying, “come over here and sit down,” try, “come here,” followed by “sit” or “please sit”

- **Use visual cues and gestures**
  Patients use their eyes more than their ears to understand the world around them. They often rely on non-verbal communication to compensate for their difficulty in understanding.

- **Limit choices**
  Alzheimer’s disease affects the area of the brain that controls decision making. Limit choices by offering one of two selections. Try not to put the patient in a position to make decisions. Instead of asking “what would you like to drink?” Try, “Would you like juice” or simply hand him/her a drink.

- **Do not argue with the patient**
  The patient truly believes what he is saying is correct. Do not argue with the person. Step back and identify the situation and do not to turn it into a combative situation.

- **Avoid complex explanations**
  They are quickly forgotten or misunderstood. Keep it simple for the residents’ and your sake and try to frame questions and instructions in a positive way.


**Habilitation Therapy**

Habilitation Therapy (HT) is a comprehensive behavioral approach to caring for people with neurocognitive disorders. It focuses not on what the person has lost due to their illness, but on their remaining abilities. HT creates and maintains positive emotional states in the person with neurocognitive disorders through the course of each day. It is considered by the Alzheimer’s Association to be a best practice for taking care of ADRD patients. (Alzheimer’s Association, 2011) Once understood through the lens of Habilitation Therapy, such knowledge becomes a powerful tool to improve safety, functioning, relationships, and general quality of life for everyone involved with a person with neurocognitive disorders. HT can be profound in its positive impact on neurocognitive disorder patients and their care partners.

HT maintains that people with neurocognitive disorders cannot leave the reality they inhabit — care partners must meet them in that world. (Alzheimer’s Association, n.d., p. 139) This means that family and other caregivers must imagine what it is like to experience visual processing as a person with a neurocognitive disorder does. It is only then that the underlying causes of difficult behaviors can be understood, and methods to prevent or limit them can be developed. For example, these might include providing additional visual cues, or clarifying or eliminating confusing ones.

Wandering is when a person with a neurocognitive disorder leaves a safe place where they are supposed to be, to strike out for... well; it’s sometimes hard to say where they believe they are going. They can quickly become lost and unable to return to safety; they can even die of dehydration or hypothermia. Due to confusion and panic, they may also assault someone who unwittingly frightens them. Wandering is a problem to be taken very seriously.

Due to their inability to perceive depth or dimensionality, Habilitation Therapy will use this knowledge to reduce or stop wandering behavior. When a large black floor mat is placed in front of every exit accessible to people with neurocognitive disorders, often their brain interprets the mat as a bottomless pit that must be avoided. Of their own accord, they may lose interest in the doors.

People with neurocognitive disorders need highly contrasting colors to pick out different objects. Painting an exit door, doorknob and its surrounding wall and trim all the same color can make an exit disappear for a person with ADRD. Installing door-to-floor top drapes on the windows -- as well as over an exit door -- and keeping the drapes shut can make the door seem like it’s just another window. This, too, can eliminate wandering. (Moore, 2010)

**Skilled Activities of Daily Living & Purposeful Engagement**

**Bathing and Neurocognitive Disorders**

Caregiving is an intimate task for many people -- and the awkwardness about helping with personal care can affect both the caregiver and the individual with neurocognitive disorders. A caregiver can make an individual feel less embarrassed about being dependent during bathing, dressing, and toileting by applying some of the recommendations listed below:
• Plan the bath or shower for the time of day when the person is most calm and agreeable. Be consistent. Try to develop a routine.

• Respect the fact that bathing is scary and uncomfortable for some people with neurocognitive disorders. Be gentle and respectful. Be patient and calm.

• Tell the person what you are going to do, step by step, and allow him or her to do as much as possible.

• Prepare in advance. Make sure you have everything you need ready and in the bathroom before beginning. Draw the bath ahead of time.

• Be sensitive to the temperature. Warm up the room beforehand if necessary and keep extra towels and a robe nearby. Test the water temperature before beginning the bath or shower.

• Minimize safety risks by using a handheld showerhead, shower bench, grab bars, and nonskid bath mats. Never leave the person alone in the bath or shower.

• Try a sponge bath. Bathing may not be necessary every day. A sponge bath can be effective between showers or baths.

3 Ways to Ease Awkward Feelings about Personal Care
By Paula Spencer Scott, Caring.com senior editor

Put the situation in perspective. A caregiving adult child, for example, can remind a parent, "Just think about all those years you did these things for me." A spouse can invoke the "for better or worse" clause, reminding his or her mate that a partnership is meant to include these moments, too. While some people with neurocognitive disorders don't mind bathing, for others it is a frightening, confusing experience. Advance planning can help make bath time better for both of you.

Give your loved one a little space to try. Even if you know the person can't manage a particular task without help, let him or her try, if an interest to do so is expressed. It can sometimes provide a measure of dignity -- and a lessened feeling of complete helplessness -- for a dependent person to at least make the attempt rather than having you rush in and do everything for him or her. Then when the struggle becomes obvious, you can gently say something like, "Here, let me help." Or, "Almost . . . try this."

Make a joke. Poke fun at a pair of absorbent underwear, the temperature of the water, the stubbornness of a sleeve that won't go on. Humor is not only distracting, it helps change the tone.

Dressing and Neurocognitive Disorders
For someone who has neurocognitive disorders, choosing what to wear, getting some clothes off and on, and struggling with buttons and zippers present a series of challenges. Minimizing dressing challenges may make a difference.

• Try to have the person get dressed at the same time each day so he or she will come to expect it as part of the daily routine.

• Encourage the person to dress him or herself to whatever degree possible. Plan to allow extra time so there is no pressure or rush.
• Allow the person to choose from a limited selection of outfits. If he or she has a favorite outfit, consider buying several identical sets.

• Arrange the clothes in the order they are to be put on to help the person move through the process.

• Provide clear, step-by-step instructions if the person needs prompting.

• Choose clothing that is comfortable, easy to get on and off, and easy to care for. Elastic waists and Velcro enclosures minimize struggles with buttons and zippers.

**Eating and Neurocognitive disorders**

Eating can be a challenge. Some people with neurocognitive disorders want to eat all the time, while others have to be encouraged to maintain a good diet.

• Ensure a quiet, calm atmosphere for eating. Limiting noise and other distractions may help the person focus on the meal.

• Provide a limited number of choices of food and serve small portions. You may want to offer several small meals throughout the day in place of three larger ones.

• Use straws (if appropriate and person does not have any swallowing concerns) or cups with lids to make drinking easier.

• Substitute finger foods if the person struggles with utensils. Using a bowl instead of a plate also may help.

• Have healthy snacks on hand. To encourage eating, keep the snacks where they can be seen.

Visit the dentist regularly to keep mouth and teeth healthy.

**Activities and Neurocognitive disorders**

What to do all day? Finding activities that the person with neurocognitive disorders can do and is interested in can be a challenge. Building on current skills generally works better than trying to teach something new.

• Don’t expect too much. Simple activities often are best, especially when they use current abilities.

• Help the person get started on an activity. Break the activity down into small steps and praise the person for each step he or she completes.

• Watch for signs of agitation or frustration with an activity. Gently help or distract the person to something else.

• Incorporate activities the person seems to enjoy into your daily routine and try to do them at a similar time each day.

• Take advantage of adult day services, which provide various activities for the person with neurocognitive disorders, as well as an opportunity for caregivers to gain temporary relief from tasks associated with caregiving. Transportation and meals often are provided.
Exercise and Neurocognitive disorders
Incorporating exercise into the daily routine has benefits for both the person with neurocognitive disorders and the caregiver. Not only can it improve health, but it also can provide a meaningful activity for both of you to share.

- Think about what kind of physical activities you both enjoy, perhaps walking, swimming, tennis, dancing, or gardening. Determine the time of day and place where this type of activity would work best.
- Be realistic in your expectations. Build slowly, perhaps just starting with a short walk around the yard, for example, before progressing to a walk around the block.
- Be aware of any discomfort or signs of overexertion. Talk to the person’s doctor if this happens.
- Allow as much independence as possible, even if it means a less-than-perfect garden or a scoreless tennis match.
- See what kinds of exercise programs are available in your area. Senior centers may have group programs for people who enjoy exercising with others. Local malls often have walking clubs and provide a place to exercise when the weather is bad.
- Encourage physical activities. Spend time outside when the weather permits. Exercise often helps everyone sleep better.

Incontinence and Neurocognitive disorders
As the disease progresses, many people with neurocognitive disorders begin to experience incontinence, or the inability to control their bladder and/or bowels. Incontinence can be upsetting to the person and difficult for the caregiver. Sometimes incontinence is due to physical illness, so be sure to discuss it with the person’s doctor.

- Have a routine for taking the person to the bathroom and stick to it as closely as possible. For example, take the person to the bathroom every 3 hours or so during the day. Don’t wait for the person to ask.
- Watch for signs that the person may have to go to the bathroom, such as restlessness or pulling at clothes. Respond quickly.
- Be understanding when accidents occur. Stay calm and reassure the person if he or she is upset. Try to keep track of when accidents happen to help plan ways to avoid them.
- To help prevent nighttime accidents, limit certain types of fluids—such as those with caffeine—in the evening.
- If you are going to be out with the person, plan ahead. Know where restrooms are located, and have the person wear simple, easy-to-remove clothing. Take an extra set of clothing along in case of an accident.
Sleep Problems and Neurocognitive disorders

For the exhausted caregiver, sleep can’t come too soon. For many people with neurocognitive disorders, however, nighttime may be a difficult time. Many people with neurocognitive disorders become restless, agitated, and irritable around dinnertime, often referred to as “sun downing” syndrome. Getting the person to go to bed and stay there may require some advance planning.

- Encourage exercise during the day and limit daytime napping, but make sure that the person gets adequate rest during the day because fatigue can increase the likelihood of late afternoon restlessness.

- Try to schedule more physically demanding activities earlier in the day. For example, bathing could be earlier in the morning, or large family meals could be at midday.

- Set a quiet, peaceful tone in the evening to encourage sleep. Keep the lights dim, eliminate loud noises, and even play soothing music if the person seems to enjoy it.

- Try to keep bedtime at a similar time each evening. Developing a bedtime routine may help.

- Restrict access to caffeine late in the day.

- Use night lights in the bedroom, hall, and bathroom if the darkness is frightening or disorienting.
Section Seven: Understanding and Working with Families and Caregivers

**Case Study 5 - When the Mind Says Goodbye**

Professional Care Strategies

Treatment of neurocognitive disorders depends on its cause. In the case of most progressive neurocognitive disorders, including Alzheimer's disease, there is no cure and no treatment that slows or stops its progression. But there are drug treatments that may temporarily improve symptoms. The same medications used to treat Alzheimer's are among the drugs sometimes prescribed to help with symptoms of other types of neurocognitive disorders. Non-drug therapies can also alleviate some symptoms of neurocognitive disorders.

- Monitor the effectiveness and potential side effects of medications given to improve cognitive function or delay cognitive decline.
- Provide appropriate cognitive enhancement techniques and social engagement.
- Ensure adequate rests, sleep, fluid, nutrition, elimination, pain control, and comfort measures.
- Avoid the use of physical and pharmacologic restraints.
- Maximize functional capacity: maintain mobility and encourage independence as long as possible; provide graded assistance as needed with ADL and IADL; provide scheduled toileting and prompted voiding to reduce urinary incontinence; encourage an exercise routine that expends energy and promotes fatigue at bedtime; establish bedtime routine and rituals.
- Address behavioral issues: identify environmental triggers, medical conditions, caregiver–patient conflict that may be causing the behavior; define the target symptom (i.e., agitation, aggression, wandering) and pharmacological (psychotropic) and non-pharmacological (manage affect, limit stimuli, respect space, distract, redirect) approaches, provide reassurance; and refer to appropriate mental health care professionals as indicated.
- Ensure a therapeutic and safe environment: provide an environment that is modestly stimulating, avoiding overstimulation that can cause agitation and increase confusion, and under stimulation that can cause sensory deprivation and withdrawal. Utilize patient identifiers (name tags), medic alert systems and bracelets, locks, and wander guard. Eliminate any environmental hazards and modify the environment to enhance safety. Provide environmental cues or sensory aides that facilitate cognition, and maintain consistency in caregivers and approaches.
- Encourage and support advance care planning: explain trajectory of progressive neurocognitive disorders, treatment options, and advance directives.
Provide appropriate end-of-life care in terminal phase: provide comfort measures including adequate pain management; weigh the benefits/risks of the use of aggressive treatment (e.g., tube feeding, antibiotic therapy).

Provide caregiver education and support: respect family systems/dynamics and avoid making judgments; encourage open dialogue, emphasize the patient’s residual strengths; provide access to experienced professionals; and teach caregivers the skills of caregiving.

**Integrate community resources into the plan of care to meet the needs for patient and caregiver information; identify and facilitate both formal (e.g., Alzheimer’s associations, respite care, specialized long-term care) and informal (e.g., churches, neighbors, extended family/friends) support systems.**

**Caregiver/Environmental Determinations**

The caregiver of the patient with neurocognitive disorders often has as many needs as the patient with neurocognitive disorders; therefore, a detailed assessment of the caregiver and the caregiving environment is essential.

1. Elicit the caregiver perspective of patient function and the level of support provided.

2. Evaluate the impact that the patient's cognitive impairment and problem behaviors have on the caregiver (mastery, satisfaction, and burden). Two useful tools include the Zarit Burden Interview (ZBI) and the Caregiver Strain Index (CSI) Tool.

3. Evaluate the caregiver experience and patient–caregiver relationship.

**Pharmaceutical Treatments**

There is no cure for Alzheimer’s disease and no way to slow the progression of the disease. Medications may help control behavioral symptoms such as sleeplessness, agitation, wandering, anxiety, and depression. Alzheimer’s disease is a progressive disease, but its course can vary from 5 to 20 years.

Medications called cholinesterase inhibitors are prescribed for the treatment of mild to moderate Alzheimer's disease. They may help delay or prevent symptoms from becoming worse for a limited time while controlling some behavioral symptoms. The medications are: Reminyl® (galantamine), Exelon® (rivastigmine), and Aricept® (donepezil). It is not fully understood how cholinesterase inhibitors work to treat Alzheimer's disease, but current research indicates that they prevent the breakdown of acetylcholine, a brain chemical believed to be important for memory and thinking. As Alzheimer's disease progresses, the brain produces less and less acetylcholine; therefore, cholinesterase inhibitors may eventually lose their effect.

No published study directly compares these drugs. Because they all act in a similar way, it is not expected that changing from one of these drugs to another will produce different results. However, an Alzheimer's disease patient may respond better to one drug than another.

Namenda® (memantine), is an N-methyl D-aspartate (NMDA) antagonist prescribed for the treatment of moderate to severe Alzheimer's disease. Studies have shown this medication may allow patients to maintain certain daily functions a little longer. For example, Namenda® may help a patient in the later stages of Alzheimer's disease maintain his or her ability to go to the bathroom independently for several more months, a benefit for both patients and caregivers.
Namenda® is believed to work by regulating glutamate, another important brain chemical that, when produced in excessive amounts, may lead to brain cell death. Because NMDA antagonists work very differently from cholinesterase inhibitors, the two types of drugs can be prescribed in combination.

**Caregivers dealing with the Diagnosis of Alzheimer's**

Caring for a person with Alzheimer's disease (neurocognitive disorders) at home is a difficult task and can become overwhelming at times. Each day brings new challenges as the caregiver copes with changing levels of ability and new patterns of behavior. Research has shown that caregivers themselves often are at increased risk for depression and illness, especially if they do not receive adequate support from family, friends, and the community.

One of the biggest struggles caregivers face is dealing with the difficult behaviors of the person they are caring for. Dressing, bathing, eating — basic activities of daily living — often become difficult to manage for both the person with neurocognitive disorders and the caregiver. Having a plan for getting through the day can help caregivers cope. Many caregivers have found it helpful to use strategies for dealing with difficult behaviors and stressful situations.

Finding out that a loved one has Alzheimer’s disease can be stressful, frightening, and overwhelming. As you begin to take stock of the situation, here are some tips that may help:

- Ask the doctor any questions you have about neurocognitive disorders. Find out what treatments might work best to alleviate symptoms or address behavior problems.

- Contact organizations such as the Alzheimer’s Association and the Alzheimer’s disease Education and Referral (ADEAR) Center for more information about the disease, treatment options, and caregiving resources. Some community groups may offer classes to teach caregiving, problem-solving, and management skills.

- Find a support group where you can share your feelings and concerns. Members of support groups often have helpful ideas or know of useful resources based on their own experiences. Online support groups make it possible for caregivers to receive support without having to leave home.

**Case Study 6 - Changes in Personality and Behavior of a Dementia Patient**

- Study your day to see if you can develop a routine that makes things go more smoothly. If there are times of day when the person with neurocognitive disorders is less confused or more cooperative, plan your routine to make the most of those moments. Keep in mind that the way the person functions may change from day to day, so try to be flexible and adapt your routine as needed.
• Consider using adult day care or respite services to ease the day-to-day demands of caregiving. These services allow you to have a break while knowing that the person with a neurocognitive disorder is being well cared for.

• Begin to plan for the future. This may include getting financial and legal documents in order, investigating long-term care options, and determining what services are covered by health insurance and Medicare.

**Home Safety and Neurocognitive Disorders**

Caregivers of people with neurocognitive disorders often have to look at their homes through new eyes to identify and correct safety risks. Creating a safe environment can prevent many stressful and dangerous situations.

• Install secure locks on all outside windows and doors, especially if the person is prone to wandering. Remove the locks on bathroom doors to prevent the person from accidentally locking himself or herself in.

• Use childproof latches on kitchen cabinets and any place where cleaning supplies or other chemicals are kept.

• Label medications and keep them locked up. Also make sure knives, lighters and matches, and guns are secured and out of reach.

• Keep the house free from clutter. Remove scatter rugs and anything else that might contribute to a fall. Make sure lighting is good both inside and out.

• Consider installing an automatic shut-off switch on the stove to prevent burns or fire.

**Driving and Neurocognitive disorders**

Making the decision that a person with neurocognitive disorders is no longer safe to drive is difficult, and it needs to be communicated carefully and sensitively. Even though the person may be upset by the loss of independence, safety must be the priority.

• Look for clues that safe driving is no longer possible, including getting lost in familiar places, driving too fast or too slow, disregarding traffic signs, or getting angry or confused.

• Be sensitive to the person's feelings about losing the ability to drive, but be firm in your request that he or she no longer do so. Be consistent—don't allow the person to drive on "good days" but forbid it on "bad days."

• Ask the doctor to help. The person may view the doctor as an "authority" and be willing to stop driving. The doctor also can contact the Department of Motor Vehicles and request that the person be reevaluated.

• If necessary, take the car keys. If just having keys is important to the person, substitute a different set of keys.
If all else fails, disable the car or move it to a location where the person cannot see it or gain access to it.

**Visiting the Doctor**

It is important that the person with Alzheimer’s disease receive regular medical care. Advance planning can help the trip to the doctor’s office go more smoothly.

- Try to schedule the appointment for the person’s best time of day. Also, ask the office staff what time of day the office is least crowded.
- Let the office staff know in advance that this person is confused. If there is something they might be able to do to make the visit go more smoothly, ask.
- Don’t tell the person about the appointment until the day of the visit or even shortly before it is time to go. Be positive and matter-of-fact.
- Bring along something for the person to eat and drink and any activity that he or she may enjoy.
- Have a friend or another family member go with you on the trip, so that one of you can be with the person while the other speaks with the doctor.

**Coping with the Holidays**

Holidays are bittersweet for many caregivers to those with neurocognitive disorders. The happy memories of the past contrast with the difficulties of the present and extra demands on time and energy can seem overwhelming. Finding a balance between rest and activity can help.

- Keep or adapt family traditions that are important to you. Include the person with neurocognitive disorders as much as possible.
- Recognize that things will be different, and have realistic expectations about what you can do.
- Encourage friends and family to visit. Limit the number of visitors at one time, and try to schedule visits during the time of day when the person is at his or her best.
- Avoid crowds, changes in routine and strange surroundings that may cause confusion or agitation.
- Do your best to enjoy yourself. Try to find time for the holiday things you like to do, even if it means asking a friend or family member to spend time with the person while you are out.
- At larger gatherings such as weddings or family reunions, try to have a space available where the person can rest, be by themselves, or spend some time with a smaller number of people, if needed.

**Visiting a Person with Neurocognitive Disorders**

Visitors are important to people with neurocognitive disorders. They may not always remember who the visitors are, but just the human connection has value. Here are some ideas to share with someone who is planning to visit a person with neurocognitive disorders.

- Plan the visit at the time of the day when the person is at his or her best. Consider bringing along some kind of activity,
such as something familiar to read or photo albums to look at, but be prepared to skip it if necessary.

- Be calm and quiet. Avoid using a loud tone of voice or talking to the person as if he or she were a child. Respect the person’s personal space and don’t get too close.

- Try to establish eye contact and call the person by name to get his or her attention. Remind the person who you are if he or she doesn’t seem to recognize you.

- If the person is confused, don’t argue. Respond to the feelings you hear being communicated, and distract the person to a different topic if necessary.

- If the person doesn’t recognize you, is unkind, or responds angrily, remember not to take it personally. He or she is reacting out of confusion.

**Choosing a Nursing Community**

For many caregivers, there comes a point when they are no longer able to take care of their loved one at home. Choosing a residential care facility — a nursing home or an assisted living facility — is a big decision, and it can be hard to know where to start.

- It’s helpful to gather information about services and options before the need actually arises. This gives you time to explore fully all the possibilities before making a decision.

- Determine what facilities are in your area. Doctors, friends and relatives, hospital social workers, and religious organizations may be able to help you identify specific facilities.

- Make a list of questions you would like to ask the staff. Think about what is important to you, such as activity programs, transportation, or special units for people with neurocognitive disorders.

- Contact the places that interest you and make an appointment to visit. Talk to the administration, nursing staff, and residents.

- Observe the way the facility runs and how residents are treated. You may want to drop by again unannounced to see if your impressions are the same.

- Find out what kinds of programs and services are offered for people with neurocognitive disorders and their families. Ask about staff training in neurocognitive disorder care, and check to see what the policy is about family participation in planning patient care.

- Check on room availability, cost and method of payment, and participation in Medicare or Medicaid. You may want to place your name on a waiting list even if you are not ready to make an immediate decision about long-term care.

- Once you have made a decision, be sure you understand the terms of the contract and financial agreement. You may want to have a lawyer review the documents with you before signing.

- Moving is a big change for both the person with neurocognitive disorders and the caregiver. A social worker may be able to help you plan for and adjust to the move. It is important to have support during this difficult transition.
Expected Outcomes

- Patient Outcomes: The patient remains as independent and functional in the environment of choice for as long as possible, the comorbid conditions the patient may experience are well managed, and the distressing symptoms that may occur at end of life are minimized or controlled adequately.

- Caregiver Outcomes (lay and professional): Caregivers demonstrate effective caregiving skills; verbalize satisfaction with caregiving; report minimal caregiver burden; are familiar with, have access to, and utilize available resources.

- Institutional Outcomes: The institution reflects a safe and enabling environment for delivering care to individuals with progressive neurocognitive disorders; the quality improvement plan addresses high-risk problem-prone areas for individuals with neurocognitive disorders, such as falls and the use of restraints.

An Alzheimer’s Disease Bill of Rights

Every person diagnosed with Alzheimer’s disease or a related disorder deserves the following rights:

- To have appropriate, ongoing medical care
- To be productive in work and play for as long as possible
- To be treated like an adult, not like a child
- To have expressed feelings taken seriously
- To be free from psychotropic medications if possible
- To live in a safe structured and predictable environment
- To enjoy meaningful activities that fill each day
- To be outdoors on a regular basis
- To have physical contact, including hugging, caressing, and hand-holding
- To be with individuals who know one’s life story including cultural and religious traditions
- To be cared for by individuals who are well trained in neurocognitive disorders care

*--From The Best Friends Approach to Alzheimer’s Care By Virginia Bell and David Troxel*
Section Eight: Recognizing and Responding to Abuse and Neglect of Individuals with Neurocognitive Disorders

Unfortunately elder abuse and neglect is a very real and concerning problem. According to an article in Dementia Today, every year tens of thousands of elderly citizens are abused. Over half a million complaints of abuse are reported each year while millions of other cases go unreported. Those individuals with neurocognitive disabilities are at greater risk of abuse and neglect than their otherwise healthy counterparts. They are physically frail and often because of their cognitive impairments they are more taxing on their caregivers, leading to increased frustration and a feeling of being completely overwhelmed. Abuse isn’t always physical. There are several types of abuse and neglect that individuals with neurocognitive disorders may become victim to.

Physical Abuse
Physical abuse is defined as an act of another party involving contact intended to cause feelings of physical pain, injury, or other physical suffering or bodily harm. The Centers for Disease Control and Prevention (CDC) defines elder physical abuse occurring when an elder is injured, assaulted or threatened with a weapon, or inappropriately restrained. Restraints can be physical or chemical.

Signs of Physical Abuse
- Unexplained signs of injury such as bruises, welts, or scars, especially if they appear symmetrically on two sides of the body
- Broken bones, sprains, or dislocations
- Report of drug overdose or apparent failure to take medication regularly (a prescription has more remaining than it should)
- Broken eyeglasses or frames
- Signs of being restrained, such as rope marks on wrists
- Caregiver’s refusal to allow you to see the elder alone

Emotional Abuse
Emotional abuse is defined as a form of abuse characterized by a person subjecting or exposing another to behavior that may result in psychological trauma, including anxiety, chronic depression, or post-traumatic stress disorder. This can include humiliation, controlling behavior such as limiting access to resources such as the telephone, transportation, and money among other things.

Signs of Emotional Abuse
- Intimidation through yelling or threats
- Humiliation and ridicule
- Habitual blaming or scapegoating
- Ignoring the elderly person
- Isolating an elder from friends or activities
- Terrorizing or menacing the elderly person
- Threatening, belittling, or controlling caregiver behavior
- Uncharacteristic behavior from the elder such as rocking, sucking, or mumbling to oneself
Sexual Abuse
According to the CDC sexual abuse or abusive sexual contact is any sexual contact against an elder’s will. This includes acts in which the elder is unable to understand the act or is unable to communicate. Abusive sexual contact is defined as intentional touching (either directly or through the clothing), of the genitalia, anus, groin, breast, mouth, inner thigh, or buttocks. It can also include forcing the individual with neurocognitive disorders to engage in watching pornographic material against their will.

Signs of Sexual Abuse
- Bruises around breasts or genitals
- Unexplained venereal disease or genital infections
- Unexplained vaginal or anal bleeding
- Torn, stained, or bloody underclothing

Neglect or Abandonment
Neglect is the failure or refusal of a caregiver or other responsible person to provide for an elder’s basic physical, emotional, or social needs, or failure to protect them from harm. Examples include not providing adequate nutrition, hygiene, clothing, shelter, or access to necessary health care; or failure to prevent exposure to unsafe activities and environments. Abandonment is the willful desertion of an elderly person by caregiver or other responsible person. Neglect can be both active (intentional) or passive (based on ignorance of amount of care an individual requires).

Signs of Neglect or Abandonment
- Unusual weight loss, malnutrition, dehydration
- Untreated physical problems, such as bed sores
- Unsanitary living conditions: dirt, bugs, soiled bedding and clothes
- Being left dirty or unbathed
- Unsuitable clothing or covering for the weather
- Unsafe living conditions (no heat or running water; faulty electrical wiring, other fire hazards)
- Desertion of the elder at a public place

Financial Exploitation
Financial exploitation is the unauthorized or improper use of the resources of an elder for monetary or personal benefit, profit, or gain. Examples include forgery, misuse or theft of money or possessions; use of coerion or deception to surrender finances or property; or improper use of guardianship or power of attorney. This type of abuse can come not only from a caregiver, but also from outside sources such as phone calls claiming the individual has won a prize put must give personal information, such as a credit card or bank account number, before claiming, phony charities and investment fraud.

Signs of Financial Exploitation
- Significant withdrawals from the elder’s accounts
- Sudden changes in the elder’s financial condition
- Items or cash missing from the senior’s household
- Suspicious changes in wills, power of attorney, titles, and policies
- Addition of names to the senior’s signature card
- Unpaid bills or lack of medical care, although the elder has enough money to pay for them
Financial activity the senior couldn’t have done, such as an ATM withdrawal when the account holder is bedridden

Unnecessary services, goods, or subscriptions

In a nursing care setting, taking the belongings of one resident to use for another (disposable briefs, clothing, etc.)

**Healthcare Fraud and Abuse**

Healthcare fraud is also a potential problem for the elderly and for those with neurocognitive disorders. This is when healthcare providers – doctors, nurses, or other healthcare professionals – take advantage of those under their care by charging for services not provided, double billing for services, getting kickbacks for prescribing certain medications over another, and over or under medicating to name a few.

**Signs of Healthcare Fraud and Abuse**

- Duplicate billing for the same medical service or device
- Evidence of over medication or under medication
- Evidence of inadequate care when bills are paid in full
- Problems with the care facility; poorly trained, poorly paid, or insufficient staff; crowding; inadequate responses to questions about care

**Risk Factors among Caregivers**

Caring for an individual with neurocognitive disorders can be very demanding. Many people who decide to take on the role of caregiver often do not realize the extent of care they have committed themselves to. As a result, caregivers can become burnt out and be at higher risk of becoming abusive. Below is a list of risk factors that can contribute to elder abuse.

**Risk Factors**

- Lack of knowledge about neurocognitive disorders
- Inability to cope with stress
- Depression
- Lack of support from other potential caregivers
- Having other caring demands from spouse or children
- Perception that taking care of the individual with neurocognitive disorders is burdensome and without psychological reward
- Substance abuse
- The severity of the care recipients cognitive impairment
- Social isolation (the caregiver and care recipient are alone together the majority of time)
- The care recipient’s role, at an earlier time, as an abusive parent or spouse
- History of domestic violence in the home
- The care recipient’s own tendency toward verbal or physical aggression

**Responding to Abuse**

As healthcare professionals, working in skilled nursing facilities, we are mandatory reporters of any type of suspected resident abuse. It is important that we be objective and factual in our reporting. Do include as much detail as possible of what you witnessed and the person(s) involved. Do not report what you think may have happened.
Case Study 8 – Mrs. Grant

Reporting Elder Abuse
When reporting a suspected case of abuse, try to include the following:

- Name of individual who may have been abused, including age and gender
- Name of facility and people responsible for the individuals care
- Identify the person you suspect of abusing or neglecting the individual
- Any other people who were involved or witnessed the abuse
- What happened
- What did you see or hear
- What was the extent of the harm
- What signs of abuse or neglect exist
- What did the resident/individual say
- What did other people say
- Have there been previous incidents

To report an incident or concern of abuse or neglect, call the Alzheimer's Association (1.800.272.3900) or Eldercare Locator (1.800.677.1116). You'll be connected to your state or local adult protective services division or to a long-term care ombudsman. You do not need to prove that abuse is occurring — it is up to the professionals to investigate suspicions.
Section Nine: Caring for the Caregiver

“Caregiving is universal. There are only four kinds of people in the world: those who have been caregivers, those who currently are caregivers, those who will be caregivers, and those who will need caregivers” ~ Rosalyn Carter

We’ve all heard it before. You’re going on an airplane for a trip and the flight attendant gives the speech at the beginning of the flight; In the case of loss of cabin pressure, and if you are travelling with small children, put the mask on yourself before assisting the child with their mask. Why is that? It is simply that if we do not take care of ourselves first, we cannot be effective caregivers for others. It may be a simple concept, but the fact is that many caregivers forego taking care of themselves and devote all of their time on the care of those in their charge. Some experience feelings of guilt if they take time out for themselves. The truth is that it is important that the caregiver take time out to regroup, recharge and reenergize. Taking on the responsibility of caring for an individual with neurocognitive disabilities can be a major lifestyle change that may last for many years. There are several things caregivers can do to keep themselves healthy during this sometimes challenging time:

See a doctor
Annual check-ups are important but caregivers should also listen to what their bodies are telling them and visit their doctor when they start experiencing any physical or mental changes. Research has shown that if you are a caregiver between the ages of 66 and 96, and experiencing mental or emotional strain, you have a 63% higher risk of dying than your otherwise healthy counterparts that are not caregivers. Depression is one of the most common conditions experienced by caregivers, but it is also a treatable condition. Here are a few symptoms that may warrant a visit to your doctor:

Symptoms of Depression
- Becoming easily agitated or frustrated
- Feeling of worthlessness or guilt
- Feelings of hopelessness
- Thoughts of death, dying or suicide
- Disturbed sleep
- Fatigue or loss of energy
- Loss of interest or pleasure in usual activities
- Difficulty thinking or concentrating
- Changes in appetite and weight
- Physical symptoms that do not respond to treatment, such as headaches, digestive disorders and pain

Physical activity
For some people physical activity is a normal part of their everyday life, for others it is something that they have never felt like they had the time, or desire, to fit it into their daily schedule. When taking on the role of caregiver, physical activity is a great way to relieve stress, promote better sleep, and increases energy. Exercise does not need to consist of an hour a day at the gym. According to the Centers for Disease Control and Prevention (CDC) for adults ages 18-64 and 65 and older, that have no limiting health conditions, the recommended amount of physical activity a week is 2 hours and 30 minutes of moderate intensity aerobic activity along with 2 days of muscles strengthening activity. That is 30 minutes of activity on most days. If taking 30 minutes out of your day all at once seems too challenging, breaking it up into 10 minute intervals throughout the day is just as beneficial.
Examples of moderate intensity exercise
- Biking slowly (less than 10 miles per hour)
- Canoeing
- Dancing
- General gardening (raking, trimming shrubs)
- Tennis
- Hand cyclers (hand ergometers)
- Walking briskly (3 miles per hour or faster, but not race-walking)
- Water aerobics

Examples of muscle strengthening activities
- Heavy gardening (digging, shoveling)
- Lifting weights (can use cans of food or whatever else you have on hand)
- Push-ups on the floor or against the wall
- Sit-ups
- Working with resistance bands

Healthy Diet
Maintaining a healthy diet is important for your overall health and for reducing stress levels. Most studies suggest limiting the consumption of red meat and focusing more on increasing intake of whole grains, fruits, vegetables, fish, nuts and other healthy fats.
**Tips for Healthy Eating**
- Plan ahead
- Eat citrus fruits for a sweet craving and the Vitamin C will work as a stress reducer
- Snack on foods rich in zinc, such as pumpkin seeds and cashews
- Drink green tea instead of coffee
- Make meals with whole grains and green leafy vegetables

Taking on the care for a person with neurocognitive disorders can be a rewarding, yet stressful, experience. It cannot be emphasized enough that it is important for the caregiving to take care of themselves, just as much as for the person they are caring for. Below are several tips on how to maintain a healthy balance while caring for someone with neurocognitive disorders.

**Suggestions for Caregiver Well-being**
- Become informed about the care recipient’s health issues and any expected changes in behavior
- Accept the facts and deal with your situation the best that you can
- Seek professional help whenever necessary
- Share the burden of caring and caregiving with family members and other interested persons
- Talk about your problems with a trusted person
- Don’t be too shy, proud, or afraid to seek help with caregiving
- Become aware of the limits of your caregiving abilities
- Maintain social activities and important relationships
- Get away from the responsibilities from time to time
- Pace yourself. You may be responsible for caregiving for many years
- Work off anger with physical activity
- Plan ahead to avoid crises where possible
- Live one day at a time
- Recognize the worst-case scenario, but hope for the best
- Join a family support group
- Keep your sense of humor
Future Outlook
There is new research currently being conducted to help impede the progression of Alzheimer’s disease, with one of the leading researchers being Dr. Reisa Sperling from Brigham and Women’s Hospital and Harvard Medical School. This latest research began its initial stage Monday, June 9, 2014 when an applicant from Rhode Island was the first person to be tested to participate in the study. The potential candidates are healthy individuals with no symptoms of memory problems often associated with Alzheimer’s disease, between the ages of 65 to 85, with increased amounts of beta-amyloid, a sticky substance that plays a key role in the development of Alzheimer’s disease in some people. The study is called the Anti-Amyloid Treatment in Asymptomatic Alzheimer’s, or the A4 Study. It will consist of 1000 participants from the United States, Canada and Australia and is expected to last for 3 years. Subjects will meet monthly with their physicians and participate in memory testing every 6 months to compare changes in cognition over time. Some participants with receive solanezumab, a drug designed to catch amyloid before it builds brain plaques that may lead to Alzheimer’s, while others will receive a placebo. Solanezumab has been trialed previously in studies with people who had full-blown Alzheimer’s. Although the drug did not help people with advanced forms of the disease, it did appear to slow the cognitive decline in people with mild Alzheimer’s. The hope is that by using the drug before symptoms begin to appear, it can help prevent, or delay, the onset of the disease. The belief is that people with Alzheimer’s often are asymptomatic for many years, similar to those with heart disease due to cholesterol build-up, before any signs of trouble begin to appear. In the United States there are currently 31 states with testing locations for potential study participants.

For more information please go to http://www.a4study.org.

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Relevant Practice Guidelines
American Occupational Therapy Association: Occupational Therapy Practice Guidelines for Adults with Alzheimer’s Disease and Related Disorder. AOTA Press. © 2010 by the American Occupational Therapy Association, Inc.
Alzheimer’s Foundation of America (AFA): Excellence in Care: http://www.alzfdn.org
Organizations

Several organizations offer information for caregivers about dementia. To learn more about support groups, services, research, and additional publications, you may wish to contact the following:

Alzheimer’s Disease Education and Referral (ADEAR) Center
P.O. Box 8250
Silver Spring, MD 20907-8250
1-800-438-4380
301-495-3334 (fax)
Web address: www.alzheimers.nia.nih.gov

This service of the National Institute on Aging is funded by the Federal Government. It offers information and publications on diagnosis, treatment, patient care, caregiver needs, long-term care, education and training, and research related to dementia. Staff answers telephone and written requests and make referrals to local and national resources. Publications and videos can be ordered through the ADEAR Center or via the web site.

Alzheimer’s Association
225 North Michigan Avenue
Suite 1700
Chicago, IL 60601-7633
1-800-272-3900
Web address: www.alz.org
Email address: adear@nia.nih.gov

This nonprofit association supports families and caregivers of patients with dementia. Almost 300 chapters nationwide provide referrals to local resources and services, and sponsor support groups and educational programs. Online and print versions of publications are also available at the web site.

Children of Aging Parents
P.O. Box 167
Richboro, PA 18954
1-800-227-7294
Web address: www.caps4caregivers.org

This nonprofit group provides information and materials for adult children caring for their older parents. Caregivers of people with Alzheimer’s disease also may find this information helpful.

Eldercare Locator
1-800-677-1116
Web address: www.eldercare.gov
The Eldercare Locator is a nationwide, directory assistance service helping older people and their caregivers locate local support and resources for older Americans. It is funded by the Administration on Aging (AoA), which also provides a caregiver resource called Because We Care – A Guide for People Who Care. The AoA Alzheimer’s Disease Resource Room contains information for families, caregivers, and professionals about dementia, caregiving, working with and providing services to persons with dementia, and where you can turn for support and assistance.

Family Caregiving Alliance  
180 Montgomery Street  
Suite 1100  
San Francisco, CA 94104  
1-800-445-8106  
Web address:  
www.caregiver.org

Family Caregiver Alliance is a community-based nonprofit organization offering support services for those caring for adults with dementia, stroke, traumatic brain injuries and other cognitive disorders. Programs and services include an Information Clearinghouse for FCA’s publications.

The National Institute on Aging Information Center  
P.O. Box 8057  
Gaithersburg, Maryland 20898-8057  
1-800-222-2225  
1-800-222-4225 (TTY)  
Web address:  
www.nia.nih.gov

The National Institute on Aging (NIA) offers a variety of information about health and aging, including the Age Page series and the NIA Exercise Kit, which contains an 80-page exercise guide and 48-minute closed-captioned video. Caregivers can find many Age Pages on the NIA Publications ordering website at www.nia.nih.gov/HealthInformation/Publications. NIASeniorHealth.gov is a senior-friendly website from NIA and the National Library of Medicine. Located at www.NIHSeniorHealth.gov, the website features popular health topics for older adults.

The Simon Foundation for Continence  
P.O. Box 815  
Wilmette, IL 60091  
1-800-237-4666  
Web address:  
www.simonfoundation.org

The Simon Foundation for Continence helps individuals with incontinence, their families, and the health professionals who provide their care. The Foundation provides books, pamphlets, tapes, self-help groups, and other resources.

Well Spouse Association  
63 West Main Street, Suite H  
Freehold, NJ 07728  
1-800-838-0879
Web address: www.wellspouse.org

Well Spouse is a nonprofit membership organization that gives support to wives, husbands, and partners of the chronically ill and/or disabled. Well Spouse publishes the bimonthly newsletter, Mainstay.

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Papers of particular interest, published within the annual period of review, have been highlighted as:
*of special interest **of outstanding interest


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