

HOSPICE MANUAL

Hospice care is appropriate for persons with dementia and allows these patients to die with comfort and dignity. End of life care is important to both the patient and the family caregiver. Most caregivers are exhausted at the time of the patient's demise and many suffer from psychiatric problems as well. This manual includes comprehensive information about end of life care for persons with dementia including appropriate use of PEG tubes, pain management and a listing of medications that can produce significant complications in persons with dementia. We recommend that all hospice workers utilize the textbook "Geriatric Dosage Handbook" in the management of the dying Alzheimer patient. Our DETA brain teaching booklet, "Crossing the River of Life with Alzheimer's" speaks to disease progression and demonstrates advanced damage to the brain in understandable language for family caregivers. These visual aids assist the family in understanding the terminal nature of the brain damage. Tape #8 in the DETA Brain Series specifically speaks to end-of-life care for persons with dementia. Additional materials can be obtained by logging onto the DETA website www.alzbrain.org.

The Deta Life Choices Program

The Need for Life Choices

Dementia is a common problem that occurs late in life. Dementia is usually a fatal disease as is growing old. The finality of life is no secret to the older persons.

Most older citizens are concerned about quality of life, independence, autonomy, and their position within the family. Most older persons will choose quality of life and position in the family over length of survival.

Every older person has the right to self-determination and these older individuals should be encouraged to express their views while they remain physically and intellectually intact. Dementia eventually robs the older person of the ability to provide guidance of life choices. Persons with mild dementia are usually capable of describing how they wish their life to be conducted. Families are encouraged to discuss these important spiritual, human, and legal issues with the older person and prepare plans for common emergencies such as health catastrophes, loss of caregiver, etc. The goal of life choices is to assure that every dementia patient has the opportunity to live a full life based on their individual wishes and desires.

Some individuals want every possible means exhausted to prolong life and families should abide by those wishes. Other individuals want limited interventions that assure continued stay at home. There are no “right” or “wrong” decisions about these life decisions. Families, healthcare providers, and other individuals should not judge the decisions made by older individuals but respect the person’s human right of self-determination.

Few older persons wish to reside in nursing homes although many will be required to receive nursing home care. Every effort should be made to sustain the older person with dementia at home for as long as possible. Less restrictive environments, such as assisted living, are preferable to medical environments, such as nursing homes, unless the patient has complex medical needs.

The Life Choice Program

The life choice program for persons with dementia includes four phases of decision-making: 1) discussions while the patient remains intellectually intact, 2) discussion during the early phases of the illness while the patient remains able to give informed consent, 3) management in the middle stages of the illness based on patient's choice, and 4) respecting the end of life directives provided by the patient.

Ageing With Dignity And Self-Determination

Most persons over the age of 65 are healthy and rate their quality of life as good. The human body is not programmed to die until age 120 or 130 and disease causes most deaths. Although genetics play some role in life span, life choices play a major role in the determination of life expectancy. As people live past age 60, they are encouraged to engage in prevention programs that reduce disease and disability. Persons over 65 have higher rates of disabling or fatal diseases such as heart disease, cancer, etc., and older individuals should begin to consider vital issues such as when heroic measures like breathing machines are appropriate to prolong their life. Most persons in this age group wish to receive aggressive therapy when there is a reasonable expectation of meaningful recovery. Many older persons would not want life sustaining measures when bodily damage is so severe as to eliminate the possibility of meaningful recovery with a good life quality. The discussion about future wishes should occur within the family, with spiritual leaders, and with the primary care physician who treats the patient. Older persons who have not considered these issues should discuss the matter prior to major surgery, e.g., heart surgery, cancer therapy, etc. Any person over age 75 should consider these matters and discuss key issues with the family. Older persons should consult with their family attorney to understand legal options for decision-making, surrogate decision-making, and other life decisions. Persons who enter later life with no advanced directives or instructions can place

tremendous burdens on family caregivers who will be forced to make decisions. This “default” decision-making can produce tremendous anxiety and guilt for family decision-makers. Even the default decision of authorizing maximum medical interventions to prolong life can produce guilt and sorrow in the decision maker. Severely debilitated, older patients may linger on life support systems for months; producing significant suffering and distress for the family and the patient. Clear directions from the older person provide the family caregiver with the comfort of knowing that the caregiver is following the wishes of the patient. Many legal issues should be discussed by the older person (**See Table 1**) and the local Office of Senior Services can provide free legal advice in the event that the person is unable to pay for consultation with an attorney to consider legal matters. Advanced planning is the ultimate expression of self-determination for the older person and the ultimate expression of love and compassion for their supportive family.

Coping with Mild Dementia

Most patients with mild dementia retain the ability to express their opinions on advanced directives and end of life care. Family caregivers and patients should discuss wishes, preferences, and legal matters while the patient retains the ability to give informed consent. All involved family should be provided an opportunity to discuss the matter with the patient to avoid family conflict later in the disease process. Every medical and behavioral intervention should be employed to maximize patient function for as long as possible. Families should recognize that patients will probably become delirious during the course of hospitalization for surgery and other procedures. Planning and directives should be completed prior to hospitalization. Family members who express concern or dispute decisions should be allowed to express themselves at family meetings where all persons are represented to include the older person with dementia. Family disagreements are better arbitrated early in the disease when the patient can express their self-determination on the matter. Family counseling can be obtained in circumstances

with significant family strife. Family discord can worsen over the course of the illness and issues of self-determination are best settled while the patient retains the ability to express their views. Unresolved family discord often produces significant distress for all involved parties. Hospitalization for the mildly demented patient can produce significant stressors and challenges to the family because patients often become significantly confused and unable to make decisions for themselves. Families can use the safe hospital's program to better prepare for this situation.

Patients with early stage dementia may develop acute medical problems, e.g., heart attack, cancer, etc. Most early stage patient can tolerate aggressive therapy to include surgery depending upon their other medical problems. Elective procedures in mildly demented patients are reasonable, especially when they improve quality of life or prolong survival. Dementia survival varies according to the individual and some persons can live many years with their cognitive loss. Consequently, the decision for elective procedures, e.g., cataract surgery, breast biopsy, colonoscopy with biopsy, etc., should be performed on a case-by-case basis; however, most mildly demented patients tolerate major surgical procedures well where the operative team accommodates the patient's cognitive limitations. Safe hospital programs for these patients are especially important to minimize the risk for delirium and post-operative debilitation.

Helping The Person with Mid-Stage Dementia

Middle stage dementia produces significant challenges and stressors to the family and the patient. Patients often develop significant behavioral problems, health problems, and functional disability such as urinary incontinence. The burden of clinical care in the middle stages of dementia often precipitate discussion within the family about whether nursing home placement is best. Families often become concerned that the burden of care for the demented patient is producing serious health consequences to the family caregiver. Many families promise loved ones

that “we will never place you in the nursing home”. Each patient, caregiver, and family is a unique situation and no single blueprint addresses each unique situation. Families should discuss these matters in advance and develop contingency plans in the event that the caregiver is unable to manage the patient or the patient requires complex healthcare needs. Families should become aware of long-term care options including sitter agencies, home health agencies, assisted living, and nursing home care.

Middle stage patients are often vulnerable to complications associated with aggressive treatment for specific health problems such as heart disease, cancer, etc. Delirium is a common problem in any post-operative patient. Mortality and disability associated with post-operative delirium is substantial. Families must weigh the potential benefits to the patient against the risk of functional loss. For instance, metastatic breast cancer patient can be aggressively treated in an otherwise healthy patient with mild dementia. The decision to treat the same level of illness in a moderately demented patient should be made on a case-by-case basis.

Elective surgical procedures in the middle stage of dementia require careful thought and consideration. Specific procedures, such as biopsies, should be preformed only when the patient is considered to be an acceptable candidate for definitive treatment based on the results of the biopsy. For instance, colonoscopy with biopsy should not be performed on a demented patient who is unable to undergo chemotherapy or surgical reception.

Middle stage patients requiring hospital care often become delirious during the course of the hospitalization. Families should prepare for hospital stay and make every effort to maximize function of the individual. The demented patient is usually unable to make informed decisions during the middle stages of the disease

and families should adhere to the expressed wishes of the patient as expressed while the patient was intellectually intact. Surrogate decision-making, advanced directives, and other preparations are essential to reducing family stress during hospitalization and maximizing adherence to the family caregiver's wishes.

Behavioral problems are common during the middle stages of dementia and these symptoms can jeopardize home care for the patient. Families should make every effort to obtain expert behavioral and psychiatric care for the person who demonstrates severe behavioral abnormalities. Caregivers should not remain at home with patients who manifest dangerous behaviors because injury for the caregiver will result in institutionalization of the patient. Aggressive treatment for behavioral problems is part of a comprehensive plan for self-determination and homebased care. Families are often confronted with difficult choices as they balance the use of medications that produce adverse effects, e.g., drowsiness, slowness, against severe behavioral problems that will eventually produce institutionalization. Families must authorize sufficient treatments to reduce symptoms balanced against quality of life for the patient. Most older persons would not wish to become a risk or threat to spouses or family caregivers when provided with the choice.

Choices at the End of Life

Late stage dementia presents family caregivers with many decisions and challenges. Advanced-stage patients forget how to walk, talk, chew, swallow, and control bodily functions. Many late stage patients require nursing home care to optimize quality of life and pain management.

Late stage dementia patients develop a broad range of health problems and medical conditions. Aggressive therapy for terminal illnesses such as cancer and heart disease may not be indicated in these individuals as the intervention may lower the patient's quality of life. Elective procedures such as cataract surgery, colonoscopy

for a non-surgical candidate should be avoided unless specific clinical criteria are present and the procedure is carefully discussed with the family decision-maker.

Pneumonia from inhaled food or saliva, i.e., aspiration pneumonia, is a common cause of death in persons with dementia. Patients begin to lose weight as they are unable to consume adequate calories to sustain life. Families are often confronted with requests or demands by long-term care facilities for the insertion of feeding tubes. Families may need to decide whether patients should receive medical care within the hospital, at home, or in the nursing home.

Feeding tube care is a complex decision that requires great knowledge on the part of the family caregiver. Individuals should consult with the feeding tube handout and “End of Life Handout for Family Caregivers”. A consultation with hospice is usually helpful in defining medical, legal, behavioral, and spiritual issues that pertain to dementia care.

The patient dying with Alzheimer’s disease and the family caregivers need intense spiritual support from their community’s spiritual family. Support groups often provide emotional assistance. Pastors and spiritual leaders have a moral and ethical responsibility to assist the caregiver family and the patient through the dying process.

Life is finite. Older persons know that they cannot choose to live forever. The older person can control their destiny by explaining their life wishes while they retain intellectual abilities.

Management of the Hospice Patient with Dementia

Richard E. Powers, MD

Dementia is a fatal illness that afflicts 10% of people over the age of 65. Over 60% of individuals in nursing homes and over half of assisted living facilities residents suffer from dementia. The number of demented persons will grow over the next 20 years as the number of elderly Americans increases.

The average life expectancy of a person with dementia is 8-10 years depending on the physical health and type of dementia. Survival duration depends on age, other health problems, quality of care, and rate of cognitive decline, i.e., intellectual loss. Hospice provides valuable services to persons dying with dementia at home, in the nursing home, or within an assisted living facility. Some demented patients may die from unrelated medical problems early in their disease, e.g., a mildly demented patient with cancer. The hospice recipient may also be a caregiver who is dying from age-related medical problems. In all cases, the hospice professional is well-equipped to provide comprehensive care when they understand the symptoms of dementia and the problems associated with caregivers. Demented patients at the end of life need the same assistance as a cognitively intact person, e.g., reassurance, pain management, optimal nutrition, etc., as well as unique assistance, e.g., behavioral management adjustment of cholinesterase inhibitors, etc.

Hospice services for persons with dementia have suffered from many obstacles placed by funding agencies, healthcare professionals, long-term care providers, and public misperception. Funding agencies seek assurances that patients will die within six months from an illness that can span an entire decade. Some healthcare professionals are hesitant to refer patients to hospice because they believe patients with advanced dementia cannot benefit from the services. Long-term care providers are confused about how nursing home or assisted living facility care

differs from hospice care. Caregivers can resist a hospice referral because of problems with denial and caregiver guilt.

Failure to use hospice services may increase patient suffering, burden the family, as well as expend financial resources on futile therapeutic interventions. Most resistance to hospice services develops because the resistive individual is not knowledgeable about the care provided at end-of-life.

Understanding the Natural History of Dementia

Hospice care helps persons dying with all types of dementia. Most dementias are progressive and terminal producing massive neurological damage or other health problems. Some demented patients may deteriorate to a certain level of disability and then stabilize; however, the vast majority of individuals continue to progress overtime. For example, patients with post-concussive dementia or alcohol-induced dementia with subsequent sobriety may remain stable over prolonged periods of time. Very old persons with Alzheimer's disease, i.e., over age 85, may progress slower than younger individuals with the same diagnosis.

The typical Alzheimer's disease patient will lose about 2 points per year from their mini-mental status exam (MMSE) score in the early stages and 2-3 points per year in the later stages. Severe dementia exists when the mini-mental is below 10. Most patients with mild dementia are capable of giving informed consent and these persons can provide guidance on advanced directives or end-of-life care. Patients with MMSE score below 15 are rarely capable of giving such consent. Caregivers are encouraged to discuss end-of-life issues with demented patients while that individual is still able to express their desires. Families are often hesitant to discuss these issues for fear of upsetting the demented individual. Patients who are approached in the proper manner rarely develop distress or anger. This discussion allows the Alzheimer patient to control their own destiny and exercise self-

determination. These issues can be discussed in terms of self-determination, future plans, and autonomy. Most older individuals recognize the finiteness of life and the elders are not disturbed over discussion of dying and end-of-life care. Families need basic information about the futility of resuscitation and feeding tubes for patients with end-stage dementia.

Common causes of death in persons with dementia include aspiration pneumonia, urosepsis, and infected decubiti. Hospice guidelines indicate that a demented patient has less than 6-months of expected life when the individual has severe expressive aphasia and repeated bouts of aspiration or fevers of undetected origin. Expressive language skills are a crude measure of swallowing competency in demented patients. Neurons in the inferior frontal cortex, i.e., Brocas area, that control language also coordinate swallowing mechanisms. Repeated bouts of fever or infection suggest unrecognized silent aspiration. Individuals who choke or cough following the rapid consumption of 3 oz. of water are at risk for aspiration.

End of Life Care for Persons with Dementia

Advanced stage Alzheimer patients with repeated bouts of aspiration do not benefit from PEG tube insertion. Multiple publications in highly respected journals discourage the use of nasogastric or PEG tubes in demented patients with advanced disease. Studies demonstrate that PEG tubes fail to improve nutrition, quality of life, longevity, or patient autonomy. Families are often under-informed about alternatives to PEG tubes, e.g., spoon feeding. The caregiver may believe that prolonged malnutrition produces severe suffering and distress (See handout, entitled “A Physician’s Guide to the Use of Peg Tubes in Managing Terminal Alzheimer’s Patients” and “The Caregiver’s Guide to Peg Tubes for Patients with Dementia”).

Many demented persons who develop life-threatening medical complications lack advanced directives. Distressed, exhausted caregivers often avoid the larger emotional burden of discussing the dying process with other family members. Most last minute decisions tend to use all available means to sustain life.

The use of cardio-pulmonary resuscitation for end-stage dementia patients is widespread and unproductive. Outcome studies demonstrate that end-stage dementia patients do very poorly by all outcome measures following CPR. The classic DNR order is often omitted because family caregivers lack the knowledge about resuscitation and the information about long-term outcomes. Excessive, aggressive life-prolonging medical interventions are usually employed because the family caregiver was inadequately educated and alternative options were inadequately depicted. Education about the natural history of dementia and the poor outcomes produced by aggressive medical interventions is essential for all members of the family who participate in patient care or decision-making. The family cannot make an informed decision unless they understand the nature of the brain damage produced by dementia (**See End of Life Issues Handout**).

Pastoral counseling often assists families with these difficult decisions. However, many pastors lack basic understanding of dementia and these well-meaning individuals may provide inaccurate advice based on misunderstanding. Hospital chaplains and local pastors can receive education (See Pastoral Care videotapes Vol. I&II on Alzheimer's Disease and Pastoral Care handout) to assist with this educational process.

End-of-life care for advanced stage Alzheimer patients requires that the hospice team understands common behavioral problems encountered in the demented patient. Aggressiveness, wandering, resistiveness, weight loss, and other common behavioral consequences are seen in patients during the dying process. The

clinical course of patients dying with Alzheimer's disease, vascular dementia, and diffuse Lewy body disease are similar and these patients benefit from similar management strategies. Antipsychotic medications should be avoided in dying patients -- especially those with diffuse Lewy body disease -- unless the clinician identifies specific psychotic symptoms that can be improved with the medication. Individuals with diffuse Lewy body dementia often become stiff with medications that block the dopamine receptor, e.g., Haldol, Risperdal.

Pain Management at End of Life

Pain management for the dying Alzheimer patient is complicated by the individual's inability to express or explain discomfort. Pain may be manifested through agitation or some other abnormal behavior (**See Management of Pain in Persons with Dementia Handout**). Alzheimer patients may require the same level of narcotics or other analgesics as other individuals with brain injury. Although some brain damaged individuals are more sensitive to narcotic analgesics, each patient must be titrated according to their individual need. Although benzodiazepines are not helpful in early disease, these medications may help the dying patient. Delirium is less problematic in the profoundly impaired patient.

The pharmacological management of pain and anxiety in patients with Alzheimer's disease is important to proper care. Dying patients with dementia experience pain like intact elders and the standard pain treatment paradigm for intact patients should be used in Alzheimer patients. Dosages may be reduced and clinicians must carefully monitor for agitation or resistiveness produced by narcotic-induced delirium. Demented patients may not be able to ask for narcotic analgesics and medications must be prescribed on a regular scheduled basis. Anxiety and stress are difficult to manage in dying, demented patients because benzodiazepines may produce delirium. Dying Alzheimer patients may be administered modest doses of short-acting benzodiazepines, such as Ativan, in the event that anxiety is present.

Benzodiazepines should be avoided for agitation or restlessness since these manifestations may actually be the symptoms of under-treated pain. Clinicians should avoid medications with low analgesic quality such as Darvon, as these may cause delirium in persons with dementia. Narcotics may produce constipation that goes unrecognized producing impaction, diminished oral intake, and agitation. Rectal impaction should be considered in the dying Alzheimer patient with symptomatic disimpaction.

Pain management is important in the majority i.e., 70% of demented dying patients, are under-treated for this disorder. The step-method progressing from non-narcotic analgesics through short-acting narcotics to long-acting narcotics is appropriate for demented patients as well as other individuals. Mild pain can be treated with acetaminophen or non-steroidal inflammatories with appropriate attention to GI distress. Moderate pain can be treated with codeine, oxycodone, or Tramadol, while severe pain should be treated with appropriate analgesics including morphine, Fentanyl patch, and oxycodone. Neuropathic pain can be treated with appropriate doses of anticonvulsants such as tegretol or neurontin (See handout, entitled “Management of Pain in Persons with Dementia”).

Caregivers need support through the dying process that accommodates the unique burden associated with Alzheimer care. Many caregivers are exhausted and disheartened by the dying process that often last 8 to 10 years. The slow cognitive disintegration of Alzheimer patients produces a piece-meal death that saddens, frustrates, and angers many caregivers. The caregiver may view the impending death of a patient with a mixture of sadness and relief that provokes guilt and self-recrimination. Caregivers need constant reassurance that their decisions are appropriate and accurate. Professional staff should validate the suffering sacrifice and devotion of the caregiver to focus their attention on positive features rather than guilt over relief of patient demise.

End of Life Care for the Mildly Demented Patient

The mildly demented patient may develop other terminal diseases that require hospice services. The end of life progression for mildly demented patients will be similar to that of persons with intact intellect. The major difference between normal individuals and demented persons who are dying from medical problems is the vulnerability to delirium and other side effects produced by medical problems, medical interventions, and pain medications. Abrupt changes of behavior or sensorium should be assessed like delirium (**See Assessment and Management of Delirium Handout**). Demented patients may need constant reminders about therapeutic interventions to assist with medical problems or discomfort. Hospitalized dying patients with mild dementia may experience more disorientation and confusion than intact patients and this problem is best managed by sitters and reassurance rather than psychotropic medications. Alzheimer medications, i.e., cholinesterase inhibitors, should be continued during the course of hospice care for Alzheimer patients until the patient's cognitive status or level of alertness is severely impaired. Abrupt discontinuation of cholinesterase therapy may precipitate abrupt loss of function and increase of behavioral problems. Patients should continue antidepressant therapy when depression was previously diagnosed.

The dying, dementia patient has the right to be informed about their diagnosis, prognosis, and management strategy. Dying patients with dementia do not require constant reminders about this fatal illness and discussing the matter is best limited to when the individual initiates the conversation.

Caring For the Caregiver

The hospice worker may encounter a caregiver who appears to manifest symptoms of medical or psychiatric deterioration. Depression, stress, anxiety and substance abuse are frequent complications encountered by the caregivers.

Caregivers may appear exhausted and depressed. Social isolation, sleep disruption, heavy physical labor and other issues can produce physical and emotional exhaustion. Caregivers with limited support networks and minimal use of support systems, e.g., support groups, respite service, etc., are at greater risks for burnout and poor care to the patient.

Caregivers with depression should receive antidepressant therapy. The combination of depression and caregiver burdens can produce significant disability for the individual. Caregivers should avoid long-term benzodiazepine therapy or sedative hypnotic therapy. Both sleep and anxiety medications eventually lose effectiveness, produce confusion, and worsen the clinical circumstances. Supportive psychotherapy provided through support groups is the best option for dealing with stress, distress, and bereavement.

Substance abuse is a serious problem in the elderly with 8% of older individuals experiencing problem drinking. Substance abuse includes alcoholism and overuse of prescription medications such as benzodiazepines, sedative hypnotics, and narcotics. Alzheimer's patients should not drink alcohol. Caregivers should avoid drinking more than one glass, i.e., 1 oz., of alcohol per day. The consumption of two or more ounces of alcohol on a consistent daily basis suggests self medication and staff should assess for depression. Caregivers may obtain duplicate prescriptions for benzodiazepines or narcotics and overuse these medications. Heavy drinking, excessive use of pain medications or benzodiazepines may manifest as weight loss, confusion, or deterioration in function for the older caregiver. Excessive use of benzodiazepines or alcohol produces increased

medical disability as well as greater risks for falls with fracture. The treatment team should address depression, anxiety, insomnia, and substance abuse in the caregiver. Caregivers with sleep disorders should be encouraged to use sleep hygiene, exercise, and other psychological interventions prior to the use of medications. Over-the-counter sedative hypnotics that include diphenhydramine, i.e., benadryl, often produce confusion in the older caregiver. Low dose Deseryl, i.e., 25-75mg, can be used to assist with sleep as well as medications like Zolpidem. Only benzodiazepines with a short half-life should be prescribed for severe sleep disruption. Long, half-life medications such as Valium and Dalmane, should be avoided as they produce daytime intoxication. Severe sleep disruption, weight loss, increased forgetfulness, or poor performance strongly suggests depression in the caregiver.

When the Caregiver is Dying

Hospice may care for intellectually intact, dying caregivers for demented patients, e.g., the caregiver wife who develops breast cancer. The dying caregiver must cope with the loss of their own life as well as the worry about the welfare and future safety of the demented patient. The hospice team should assist the dying caregiver with planning for the future care of the demented patient. The dying caregiver may need legal, financial, and social services advice as well as assistance with family issues.

The Alzheimer patient may wish to know about the circumstances or welfare of the dying caregiver. The clinician should provide initial information but future discussions should depend on the response of the demented individual. Patients who develop catastrophic reactions to information about the dying caregiver should be managed through distraction and redirection when future questions are asked; however, all patients have the right to accurate information about their loved-one.

Can Demented Patients Attend Funerals

The decision to include a demented patient in the planning or activities of a funeral depends on the patient and their response to the dying process. In general, mild or moderately demented Alzheimer patients should be allowed to participate in appropriate ceremonies or activities, e.g., wakes, visitation, etc. Patients with mild or moderate dementia may experience a grief reaction. The intensity of the bereavement may vary according to the cognitive status of the patient. Advanced-staged dementia patients rarely benefit from involvement in such activity; however, participation can be determined by discussion with the family. Following the death of a caregiver, the demented patient may continue to insist that the individual is alive and healthy. Families should not repeatedly dispute this assertion, but rather redirect the individual to discussion about other issues. Repeated reminders for an amnesic patient about the death of a loved one simply cause the patient to relive pain and suffering without resolution of the grief reaction. Mildly demented patients will sustain a grief reaction. Family and friend should provide the same spiritual and emotional support needed by persons with normal intellect. Physicians should avoid benzodiazepines and sedative hypnotics unless the risk of delirium is worth the benefit to the patient.

The Three-Step Method to High Quality End of Life Care			
STEP	CLINICAL FOCUS	STAGE	TREATMENT GOAL
STEP 1	Self-determination	Early	Self-determination
STEP 2	Functional Maintenance	Middle	Disease Management
STEP 3	Quality of Life	Late	Hospice Care

End-of-Life Care

Physicians Guide to The Role of PEG Tubes in Management of the Terminal Alzheimer Patient

Richard E. Powers, MD

Clinicians are often confronted with management decisions for demented patients who no longer retain the ability to maintain adequate weight through oral intake. Swallowing problems are common in nursing home residents and this disability is very common in advanced-stage Alzheimer patients. Most demented patients who develop expressive aphasia also demonstrate problems with silent aspiration. Swallowing dyspraxia and aphasia generally occurs after 5 to 7 years of illness.

Weight Loss in Dementia

The weights of nursing home patients are carefully monitored and nursing home staff becomes concerned about weight loss exceeding survey guidelines (See Table 1). Many assisted living residents or home-bound elders also suffer undetected weight loss. Demented patients with swallowing dyspraxia require large amounts of staff time for feeding and hydration. Families can become alarmed over swallowing difficulty and pressure physicians or nursing staff to “do something for Momma”. Studies on PEG tube usage in patients with end-stage dementia show that families are often encouraged to allow insertion of PEG tubes by medical staff.

Pharmacological intervention can improve oral intake when patients are not swallowing-impaired. Medications like megastrol acetate and dronabinol can increase calorie intake in patients who are able to chew and swallow (See Table 2).

The Role of PEG Tubes in Nutritional Management

PEG tubes may be helpful in patients with mild to moderate dementia who have developed swallowing problems as part of some other temporary problem, e.g.,

delirium, stroke, etc. PEG tubes may be beneficial in sustaining nutrition while the patient recovers physical vitality and swallowing function. Patients with moderate or severe expressive aphasia are at greater risk for developing silent aspiration. Coughing or choking during the drinking of 3 oz. of water increase the likelihood of aspiration. Most swallowing dyspraxias occur slowly and abrupt onset of choking suggests a stroke, delirium, or other new neurological problems.

Limitations of Effectiveness for PEG Tubes

Numerous studies and reviews demonstrate that PEG tubes are not effective for end-stage dementia patients. Studies show no substantial improvement in quality of life, life expectancy, or long-term nutritional status. Review articles consistently discourage the use of PEG tubes in dying Alzheimer patients and emphasize the use of hospice services to manage the dying process. Appetite stimulants do not improve feeding in end-stage dementia. Some stimulants may cause delirium (**See Table 2**). PEG tubes can produce serious or life-threatening complications like peritonitis or prolonged restraints (**See Table 3**).

Hospice Care for Persons Dying with Dementia

Families and nursing home staff are often hesitant to use hospice because of misunderstandings about treatment provided through the hospice management system. Families and nursing home staff often misunderstand the active therapy provided by hospice to meet the physical, mental, and spiritual needs of both the dying patient and the family caregivers. Studies show that demented individuals with severe cognitive loss, expressive aphasia, and recurrent infection, i.e., pneumonia, have a life expectancy of 6-months and qualify for hospice care. Physicians are justified in referring the patient and family to hospice when these published criteria are met.

Hospice care provides many services including management of pain, behavioral problems, nutrition, hydration, and family bereavement. The comprehensive management strategies for pain and anxiety continue to be important for persons with dementia. Although cortical damage may reduce a demented person's ability to describe and experience some qualities of pain, discomfort is probably still registered at the thalamic level in demented persons. Pain is often manifested as abnormal behavior, e.g., resistiveness, hostility, and appropriate pain management is essential to any dying patient with Alzheimer's disease. Under-treated pain and depression are common causes of weight loss in demented residents.

Complications Associated With PEG Tubes

Insertion of a PEG tube can produce several unpleasant consequences (Table 3). First, the procedure has inherent risks in debilitated patients and these individuals are at high risk for post-operative delirium. Second, residents who dislodge the tube are often managed with binders or restraints. Third, the loss of feeding and hydration produces further social isolation and lack of human contact as staff must simply "hang another bag". The family of a PEG tube recipient may not receive the counseling and spiritual support provided by the hospice team. Patients who undergo PEG tube placement continue to suffer from aspiration pneumonia requiring further interventions, e.g., IV antibiotics, IV hydration, hospitalization, etc. Other medical complications such as decubiti, contractures, etc., progress in the patient.

Research shows that families often ignore end-of-life issues until a crisis occurs. Family members should be encouraged to discuss these issues with elders while the patient retains the intellectual function to express their self-determination. Family discord is often avoided by thoughtful discussion and careful education of all family participants. Family educational material is available to physicians or

caregivers via the website www.alzbrain.org or by calling 1-800-457-5679.

Families who understand the natural history of dementia and the severity of brain damaged produced by the diseases are more likely to express reasonable opinions with regards to resuscitation, heroic measures, and end-of-life care. Most elders choose quality of life and personal dignity over longevity and survival. Self-determination and autonomy is achieved for elders by soliciting their opinions while they are capable of providing informed consent.

Dealing with Difficult Family Situations

Physicians are sometimes placed in difficult positions by families who insist they violate advanced directives that were legally and ethically executed. Physicians are duty-bound to follow advanced directives dictated by the older person. In the situation where a family member demands that the physician disregard a legally executed advanced directive, the unhappy family member can be instructed to immediately hire an attorney and file for an emergency order in the appropriate court so that the judge will instruct the treating physician to disregard the advanced directive. Families can be given this option by the treatment team and those individuals can choose whether they wish to hire an attorney and seek an immediate court order. Such orders can be achieved within a matter of hours from circuit court, although most judges will inform the petitioner that the treatment team must follow the legally executed wishes of the older individual.

Physicians play a crucial role in end-of-life care. Most families make the right decision for their loved-one when the family members understand the natural history of dementia and limitation of aggressive treatment.

Table 1
Involuntary Weight Loss Triggers

<ul style="list-style-type: none"> ▪ 5% in 30 days ▪ 10% in 180 days ▪ BMI ≤ 21 or ▪ > 25% uneaten food for 2/3 meals over 7 days
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Table 2
Effectiveness and Toxicity of Appetite Stimulants in Dementia

Medication	Dose	Effect	Toxicity
Periactin	N/A	None	Delirium
Megace	800	↑ Weight ↓ Cytokines	↑ BS DVT
Dronabinol	2.5 bid	↑ Weight	Mild delirium

Table 3
Common Complications of PEG Tubes

Complication	Consequence to Patient
1. Occlusion	Reinsertion
2. Internal Displacement	Peritonitis Reinsertion
3. Removal	Reinsertion Restraints

Quick Facts for Clinicians on Peg Tubes in Patients with End-Stage Alzheimer's Disease

1. PEG tubes rarely prevent aspiration pneumonia.
2. PEG tubes rarely improve long-term nutrition or quality of life
3. Appetite stimulants rarely work in advanced-stage dementia.
4. Some demented patients may remove or dislodge the PEG tube.
5. Most elders desire the best quality of life rather than the longest duration of life.
6. Repeated aspiration pneumonia with advanced dementia predicts six-month survival.
7. Family members do not have the legal authority to verbally change a patient's legal advanced directive.
8. Hospice is the best option for end-stage patients with swallowing dyspraxia.
9. Most families decline PEG tubes when they understand the natural history of dementia.
10. Hospice is active treatment for dying Alzheimer patients and their family caregivers.

END OF LIFE CARE FOR PERSONS WITH PARKINSON'S DISEASE

Parkinson's disease is a neurodegenerative disorder that afflicts approximately 1% of persons over the age of 65. Parkinson's disease also affects individuals as young as age 30. Parkinson's disease produces three broad categories of symptoms including motor impairment, psychiatric disability and intellectual decline. The life expectancy of a person with Parkinson's disease depends upon the age of the individual, pre-existing healthcare problems and the combination of disabilities produced by degenerative process. The life expectancy also depends upon the kind of brain pathology that produces the symptoms of parkinsonism. Parkinsonism is a non-specific clinical term that refers to stiffness, slowness, and rigidity. The three most common causes of parkinsonism include medications, idiopathic Parkinson's disease, and progressive supranuclear palsy. A range of other degenerative diseases can also produce symptoms of parkinsonism. Each disease entity has a specific life expectancy and natural history. Most neurodegenerative diseases that produce parkinsonism are fatal. These diseases produce problems with thought and judgment in the latter stages of the disease that limit the person's ability to give informed consent. Medications may also worsen the patient's intellectual abilities. Psychiatric complications, e.g., depression or delusions, may diminish a patient's capacity to give informed consent in later life.

Some clinical features suggest a reduced life expectancy for patients with Parkinson's disease. Early onset, severe rigidity, and early onset of intellectual or psychiatric problems, are unfavorable signs. Newer treatments, such as stereotactic surgery, electrical stimulation, and cell implants may extend function and survival; however, this data is incomplete.

End-of-life management for persons with Parkinson's disease begins while the patient is still physically and intellectually intact. Family and clinician should

discuss possible complications and outcomes with the patient. Specific interventions such as resuscitation, PEG tube placement, and ICU care require careful discussion and family education. Patients must not be pressured to make an immediate decision, but rather should consider these life options and discuss them with family or spiritual leaders. The caregiver and clinician should avoid decision-making during crisis situations and the advanced discussion allows the patient to determine the course of their life.

Patients with end-stage Parkinson's disease can develop several fatal complications. Most Parkinson's patients develop dysphagia and oral manifestation after year 6 of the disease and these individuals are at high risks for aspiration pneumonia. Severely rigid patients develop skin integrity problems with decubiti that can produce life-threatening infections.

Weight loss in the end-stage Parkinson's patient requires careful evaluation to determine the cause and the treatment (Table 1). Parkinson's disease does not cause weight loss; however, the complications of this brain injury will reduce the patient's ability to eat. Patients may stop eating because of depression, delusions about food, motor problems associated with feeding or dementia that causes choking or swallowing difficulties. Unrecognized medical problems such as infections, malignancies, etc., can also produce significant wasting. Appetite stimulants should not be used unless a careful evaluation excludes treatable causes and efforts are made to assist the patient with feeding. An adequate evaluation includes a medical assessment, psychiatric assessment, dietary evaluation, and a speech-language assessment of swallowing function. Appetite stimulants, like megase or Dronabinol, may improve appetite but each medication can produce complications. Periactin is not effective and produces confusion (**See Table 2**).

Feeding tubes can be used in patients with acute health care problems who are expected to recover function. Feeding tubes have not been shown to be effective in patients with advanced end-stage disease or other neuropsychiatric complications such as dementia as these invasive procedures produce complications. Demented, parkinsonian patients with severe motor impairment are best managed through hospice care. The anti-parkinsonian medications rarely cause weight loss or problems with chewing or swallowing. Likewise, further increases of anti-parkinsonian medications are unlikely to produce weight gain unless the weight loss was produced by motor impairment.

Parkinson's disease does not diminish a patient's appreciation for pain or reduce their suffering. The masked faces and motoric slowing may diminish the external manifestations of pain; however, the patient appreciates this discomfort as keenly as individuals who have normal brains (See Pain Management Handout).

The motor deficits produced by Parkinson's disease can produce stiffness contractures, muscles aches, and other symptoms of pain that require appropriate therapy. The WHO Three Step Method for narcotic analgesic prescription is most appropriate for persons with Parkinson's disease; however, these brain damaged individuals are at greater risks for developing delirium, especially from drugs with high anticholinergic profiles such as Demerol and Talwin. Parkinson's disease patients are at higher risks for developing bowel immobility and narcotic analgesics may produce rectal impaction. Proper hydration, dietary fiber, and stool softeners can eliminate this troublesome complication that can produce confusion, agitation, and pain in the parkinsonian patient.

Most Parkinson's patients are treated with multiple drugs to enhance brain dopamine as well as psychotropic medications to treat depression, anxiety, psychosis or intellectual loss. Medications are expensive and problematic for

patients with swallowing disorders. End-stage immobile patients may benefit from drug reductions in all classes of medications. Dose reduction of antiparkinsonian medications should commence with anticholinergic agents such as symmetryl or cogentin and proceed to other medications that directly stimulate the D2 receptor or alter the metabolism of dopamine, e.g., deprenyl. Drugs should be slowly tapered to assess for possible side effects. Carboxydopa preparations, i.e., sinemet, should be the last medications withdrawn under a dose simplification program. Drug reductions should stop when patients manifest worsening of motor symptoms, agitation, or other evidence of distress. Patients who develop hallucinations or delusions in the end-stage of Parkinson's disease should be treated with antipsychotic medications that do not increase stiffness or rigidity. Quetiapine has the lowest EPS profile with Zyprexa a close second. Patients with end-stage disease may tolerate antipsychotic dose reductions; however, the clinician should watch for re-emerging of symptoms including agitation, distress, or resistiveness. Many patients with anxiety symptoms early in their dementia may tolerate dose reductions for benzodiazepines in the latter stages of the illness.

Many end-stage Parkinson's disease patients go to the hospital for medical complications, e.g., bowel obstruction, and these individuals have medications discontinued during the course of their hospitalization. Psychotropic medications can be help upon discharge for patients in hospitals for more than a week without target symptoms for the psychoactive medications. For example, patients who are previously managed on an antipsychotic should not have renewal of the medication unless active symptoms return. Some patients may tolerate total discontinuation of medications while others may develop symptom relapse 6 or 12 months after hospitalization. These individuals may require lower doses of medication to maintain appropriate symptom control. Patients with severe, dangerous behaviors may require immediate resumption of medication following discharge. Decisions are made on a case-by-case basis.

Dementia is a common occurrence in the latter stages of Parkinson's. Psychosis is another common latter stage symptom with vivid hallucinations or delusions. The combination of psychosis with cognitive impairment is suggestive of diffuse Lewy body disease. Patients also develop depression, anxiety disorders, and sleep problems. Careful psychotic care can improve the quality of life for advanced-stage patients.

The success of CPR in advanced life support techniques for patients with Parkinson's disease is unknown. Aggressive medical and surgical interventions are appropriate for persons with mild disease because these individuals may have a significant life expectancy, i.e., 5-10 years. CPR or aggressive medical interventions are probably unwise for persons with end-stage disease. The motor and cognitive disability reduces the likelihood that patients can comply with essential interventions such as weaning from the ventilator, wound care for surgery, etc.

Recurrent hospitalization for end-stage Parkinson's patients may produce more harm or discomfort than good. Families and clinicians should carefully assess the value of each hospitalization in contrast to the discomfort associated with unfamiliar surroundings and caregivers.

Table 1

Involuntary Weight Loss Triggers

- | |
|---|
| <ul style="list-style-type: none">▪ 5% in 30 days▪ 10% in 180 days▪ BMI \leq 21 or▪ > 25% uneaten food for 2/3 meals over 7 days |
|---|

Table 2

Effectiveness and Toxicity of Appetite Stimulants in Dementia

Medication	Dose	Effect	Toxicity
Periactin	N/A	None	Delirium
Megasterol Acetate	800	↑ Weight ↓ Cytokines	↑ BS DVT
Dronabinol	2.5 bid	↑ Weight	Mild delirium

DIFFUSE LEWY BODY DISEASE

Diffuse Lewy body disease (DLBD) is a common neurodegenerative disorder that produces dementia, psychosis and abnormalities of movement. Clinicians began to recognize diffuse Lewy body disease in the early 1990's although this disorder has been present in the population as long as other types of dementia. In fact, this disorder may produce 10-20% of all dementia in the United States, either alone or with other dementias like Alzheimer's disease. Clinicians have limited ability to recognize this disorder, as the symptoms resemble Alzheimer's disease.

The clinical manifestations of diffuse Lewy body disease include dementia, visual hallucinations, and a fluctuating clinical course. The dementia associated with diffuse Lewy body disease can resemble Alzheimer's disease and neuropsychological testing cannot distinguish these disorders with absolute accuracy. Visual hallucinations are a common early symptom in diffuse Lewy body disease. Many patients demonstrate a fluctuating clinical course from day to day in which the level of intellectual function and the severity of hallucinations may vary from mild to severe.

Patients with DLBD frequently manifest symptoms of Parkinson's disease including stiffness, slow shuffling gait, and tremor. The symptoms of Parkinson's disease may precede the symptoms of dementia or psychosis. Patients with DLBD are often sensitive to the side-effects of neuroleptic medications, e.g., Haldol, Prolixin, etc. A psychotic patient with DLBD may receive a small dose of antipsychotic medication, e.g., Haldol, to lessen visual hallucinations, and develop severe drug-induced Parkinsonism.

The progression of symptoms of DLBD resembles that of Alzheimer's disease with a slow insidious onset followed by a gradual, relentless decline in function. The duration of survival is similar to Alzheimer's disease.

The general physical examination in patients with DLBD is unremarkable. The neurological examination may demonstrate evidence of Parkinsonism but no focal neurological deficits. Laboratory studies for DLBD are unremarkable. Brain imaging studies may demonstrate mild to moderate atrophy or an otherwise normal brain. SPECT studies are helpful to identify DLBD and usually lack the distinctive findings of decreased flow to the left parietal temporal region that is present in Alzheimer's disease.

The cause of DLBD is unknown. Genetics seem to play a minor role in the development of this disorder. Other risk factors associated with Alzheimer's disease, e.g., low educational achievement, post-menopausal estrogen deficiency, etc., do not appear to apply to DLBD. Drinking is not associated with this disorder.

Treatment is not available for DLBD; however, specific symptoms produced by the brain damage will respond to appropriate medications. Patients with symptoms of Parkinsonism will respond to appropriate doses of anti-Parkinsonian medications, e.g., Sinemet. Visual hallucinations will respond to antipsychotic medications; however, clinicians must avoid producing more Parkinsonism. Atypical antipsychotic medications such as Seroquel (quetiapine) or Zyprexa (olanzapine) are effective in lessening visual hallucinations. Low-potency neuroleptics such as Mellaril are also effective. Many patients develop depression that is improved with standard antidepressant therapy such as serotonin reuptake inhibitors. Families should be referred to Alzheimer's support groups, as social and family problems are identical in both diseases.

Anti-Alzheimer's medications such as Aricept are probably not effective in DLBD; however, patients with mild to moderate impairment may warrant a trial with the

medication because the patient may also have combined Alzheimer's disease. Preventive interventions for Alzheimer's disease such as Vitamin E, Selegiline, and Ginkgo, are not shown to be beneficial to patients with DLBD.

The brain pathology of DLBD is markedly different from other types of dementia. Microscopic brain finding of DLBD are very subtle and easily overlooked by general pathologists. Special stains must be performed to identify the characteristic circular inclusion present in the neurons of the temporal lobe, frontal lobe, and brain stem. These circular inclusions are called Lewy bodies and these structures resemble those present in Parkinson's disease. Many patients with DLBD also have the brain pathology of Parkinsonism.

Significant numbers of patients with Alzheimer's disease also have Lewy bodies in their brain. These mixed dementias are impossible to identify in the living patient and the interaction between DLBD and SDAT is unclear.

FACT SHEET ON DIFFUSE LEWY BODY DISEASE (DLBD)

1. DLBD is the second or third most common cause of dementia.
2. Intellectual loss in DLBD resembles Alzheimer's disease.
3. Most patients have visual hallucinations.
4. Confusion and hallucinations often vary on a day-to-day basis.
5. Many patients develop Parkinsonism with stiffness, slowness and tremor.
6. Many patients develop depression.
7. DLBD is not inherited.
8. There is no prevention for DLBD.
9. DLBD patients are very sensitive to antipsychotic medications, e.g., Haldol.
10. Diagnosis requires brain autopsy examination.

THE CAREGIVER'S GUIDE TO PEG TUBES FOR PATIENTS WITH DEMENTIA

By Richard E. Powers, MD

Most demented patients lose the ability to chew or swallow in the latter part of the disease. As the patient loses weight, the family must decide whether to insert a tube for feeding. Patients with swallowing problems may develop difficulties with choking or discomfort during feeding. These symptoms slowly appear in the later phases of the disease and appear to worsen after 6 or 7 years of intellectual decline. Abrupt onset swallowing problems suggests some other problem, e.g., stroke. Patients may develop feeding problems during episodes of temporary confusion from medical problems. Families may wish to insert a feeding tube to increase patient comfort, improve nutrition, reduce suffering, or simply out of frustration over inability to help the patient.

About Swallowing Problems:

Alzheimer disease and most dementias are deadly diseases that produce ongoing brain damage. Most demented individuals eventually lose the ability to walk, talk, chew, swallow, and control bodily functions like bowel or bladder. Although modern medicine can prolong the life of persons with dementia, doctors cannot maintain the quality of that life. Families must weigh the burden of suffering against the duration of life.

Families are often confused about feeding tubes and other aspects of end-of-life care. Some families choose to insert PEG tubes because of guilt, inadequate information, or worry that others will believe they let their family member die. Physicians often avoid discussions about the sad, painful subject of dying from dementia. Studies show that families rarely remove a tube once inserted into the patient. Family decision-making is easier when caregivers receive a complete

description of the progressive brain damage from dementia, problems associated with PEG tubes, and the benefits of hospice care for Alzheimer patients.

Feeding tubes inserted through the nose or the mouth, called NG or nasogastric tubes, are not a reasonable option for long-term care. These tubes cause significant discomfort and produce serious medical complications such as pneumonia. Long-term feeding via the vein is not a reasonable option because limited nutrition is provided and the veins soon become so damaged that the patient can no longer tolerate the constant sticking to insert the catheter.

About the PEG Tube:

The term “PEG” tube stands for percutaneous endoscopic gastrostomy tube. Percutaneous means the clinician must create a hole in the abdominal skin and muscles as well as a hole in the stomach. Endoscopic means that a viewing tube is inserted through the mouth into the stomach to guide the feeding tube into place. The insertion of a PEG tube requires sedation of the patient and a surgical procedure. A flexible tube, i.e., endoscope, is threaded into the patient’s stomach through his mouth. A second tube is inserted through the skin and muscles below the rib cage on the left side and through the space between the abdominal muscles and the stomach called the peritoneal space. The tube is then punched into the stomach cavity. The PEG tube is about the size of a large drinking straw and some have a balloon on the end to anchor the tube inside the stomach cavity. This procedure takes about 30 minutes although the effects of the sedation can last hours to days. Problems can occur with bleeding and infection; however, the procedure is usually safe. Up to 1/3 of patients may suffer a complication or die within 30 days of the procedure. Older dementia patients have greater risk for complications. The tube is designed to bypass the mouth and food pipe and inject the liquid nourishment directly into the stomach and intestines. This tube allows

the patient to receive nutrition without the risk of inhaling food or choking. The tube also eliminates any pleasure associated with eating or drinking.

The use of PEG tubes can help demented patients who have short-term swallowing problems that are expected to improve over time, for example, a patient with a stroke who is improving. These tubes are rarely helpful in end-stage dementia patients who are dying from advanced brain damage.

Studies show that PEG tubes provide little comfort or assistance to end-stage Alzheimer patients. The tube will prevent choking on food because the patient is not longer allowed to eat. The patient will continue to choke on saliva because they have forgotten how to swallow these bacteria-rich liquids. Inhaling saliva causes patients to have pneumonia, termed “aspiration pneumonia”. These repeated chest infections require the patient to receive antibiotics and other therapy to avoid dying from pneumonia. The use of PEG tubes in persons with advanced dementia does not prolong life expectancy and the patient’s nutritional status is not significantly improved. A few individuals may enjoy some relief or comfort from the tube; however, most demented individuals derive little benefit.

The section of the tube outside the abdominal skin must be securely positioned on the abdominal wall to prevent displacing the inner tube. Patients often require binders, i.e., abdominal girdles that cover the tube and prevent them from pulling at the device. When a tube is accidentally removed, the patient may require a second procedure for reinsertion of the feeding device. Patients often pull on the tube because the hole in their outer skin and muscle can become irritated, inflamed or infected. When a tube is only partly displaced, the feedings may get into the abdominal cavity around the stomach producing serious medical complications.

Most end-stage Alzheimer patients who can no longer chew or swallow have less than 6 months of expected life. Invasive procedures like PEG tubes rarely provide significant comfort or symptom improvement. The insertion of a PEG tube removes the need to orally feed or hydrate Alzheimer patients and the patient now loses the human contact provided by the feeding process. The tube is connected to a bag that is attached to a pump and the feeding is infused 2 or 3 times per day. The human contact associated with feeding and drinking is severely reduced because the machine cares for the patient.

The Hospice Alternative

The alternative to feeding machines is hospice care. Hospice services provide active treatment for dying Alzheimer patients. An experienced hospice team that includes doctors, nurses, and other specialists will help the patient and the family through the final stages of living. Hospice staff are trained to manage physical, mental, and spiritual suffering associated with end-of-life care. The hospice team will not withhold food or drink from the dying patient. The team will adjust feedings and hydrations to optimize patient comfort. Eventually, the patients will stop eating and drinking. Advanced-stage Alzheimer patients will drift into a sleep-like state. These individuals rarely experience ongoing starvation or thirst. The hospice team is trained to recognize any discomfort or anxiety and appropriately relieve those symptoms. Hospice staff will typically coordinate care with family and staff to assure that everyone's human and spiritual needs are met.

Family Responsibility

Caregivers are often overwhelmed by decisions on end-of-life care. Families should never be pressured or rushed into making these crucial decisions. Family should consult with pastors and carefully consider each treatment option. Family members should voice opinions after they learn the facts about dementia and the brain damage produced by these deadly diseases. Hospice treatment is active

therapy provided by trained professionals. Families should always consult with a hospice team to determine all possible treatment options for the end-stage patient.

Respecting the Patient

Dementia is a terminal disease. Families are encouraged to discuss end-of-life issues with the demented person while the patient still retains their intellectual ability. Caregiver should honor the directions and requests of persons with dementia who can speak clearly and understand the issues. Extending life is not as important to most older persons as assuring quality, dignity, and comfort.

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ALCOHOL-INDUCED DEMENTIA

Overview

Alcohol induced dementia is the third or fourth most common type of intellectual loss in older persons. Alcoholic dementia is produced by long term heavy drinking that directly damages brain cells or causes health problems that produce brain damage. Alcohol abuse is common in older persons. Eight percent of elders have a serious drinking problem. Sixty percent of elders drink and some elders (5-10%) are binge drinkers. Medicare spends more money on alcohol related problems than the treatment of heart attacks, i.e., myocardial infarctions. Alcohol related dementia is under-diagnosed because primary care doctors fail to recognize alcoholism in majority, (i.e., 60%) of older patients. Families adopt the “let granny have her drinks” attitude that prolongs heavy drinking amongst older persons.

End of Life Issues

The patient with end-stage alcohol-induced dementia often resembles that of other dementias, e.g., Alzheimer’s disease. The clinical course of alcohol-induced dementia depends upon the severity of end-organ damage such as liver disease, heart disease, and pancreatitis. The precipitous decline of a person with alcohol-induced dementia suggests that other disease processes may occur. Individuals with alcohol-induced cirrhosis are at greater risks for hepatic cellular carcinomas. Individuals with past history of pancreatitis as well as all alcoholic patients are at higher risk for pancreatic carcinoma. The demented patient with pancreatic carcinoma would lose weight and demonstrate pain-related behaviors.

Basic Information on Alcohol-Induced Dementia

The diagnosis of alcohol related dementia requires a careful clinical history and physical examination. The DSM-IV states that patients with alcoholic induced dementia must have sufficient cognitive deficits to meet criteria for dementia and a history of substance abuse based on clinical history, physical examination, or

laboratory studies. The clinical manifestations of alcohol induced dementia resemble those of other types of dementia and this diagnosis can not be confirmed with a simple clinical history. Patients develop memory problems, language impairment, and inability to perform complex motor tasks, like dressing. Patients cannot be diagnosed with dementia while they are in withdrawal or experiencing serious medical complications resulting from the substance abused, e.g., liver failure, GI bleed.

Psychiatric problems are common in patients with alcohol induce dementia. These patients develop apathy, irritability, and resistiveness that result from damage to the frontal lobes.

Korsakoff's psychosis (KP) is frequently confused with alcoholic dementia. KP is not a dementia but rather a pure amnesia. The KP patient has severely impaired short-term recall but his patient has excellent long-term memory and other intellectual functions. Patients with KP should be treated with thiamin but this amnesia is usually permanent.

Alcohol abuse will worsen intellectual and psychiatric symptoms in patients with other types of dementia. Alzheimer's or vascular dementia patients should not be allowed to drink except for ceremonial situations such as weddings, etc.

The physical examination of a patient with alcohol induce dementia may reveal evidence of neurological damage from heavy drinking. Heavy alcohol abuse damages the nerves in arms and legs, i.e., peripheral neuropathy as well as the cerebellum that controls coordination i.e., cerebellar ataxia. These patients frequently have problems with sensation in their extremities and may demonstrate unsteadiness on their feet. Alcohol also damages the heart and liver. These individuals may have abnormalities of liver studies and heart damage termed

“alcoholic cardiomyopathy”. This heart damage may produce additional brain complications such as strokes or hypo perfusion, i.e., low blood flow to the brain.

Brain imaging or other clinical studies are not helpful in distinguishing alcoholic dementia from other diseases. Neuropsychological testing can sometimes help clarify this diagnosis.

Psychiatric manifestations may proceed intellectual loss in some patients. Alcohol induced dementia can produce any type of psychiatric problem associated with dementia to include psychosis, depression anxiety, and personality changes. Patients with alcoholic dementia often develop apathy related to frontal lobe damage that may mimic depression. These individuals become irritable or resistive when caregivers attempt to assist with basic care. These individuals also demonstrate impulsive hostile behavior that requires medication.

The brain changes associated with alcohol are very non-specific. The lack of specific brain pathology has caused alcohol-induced dementia to be under-recognized as a cause of intellectual loss. Alcohol damages neurons, i.e., brain cells, throughout the brain; however, the frontal lobes and cerebellum are particularly prone to injury.

Treatment of alcoholic dementia requires sobriety, vitamin replacement, correction of medical problems, and management of behavior problems. The brain damage produced by alcohol may be arrested by cessation of drinking. Prolonged periods of sobriety for patients with alcohol induced dementia may result in slow small improvements of intellectual function. Unlike Alzheimer’s disease where patients lose two or three points on their mini mental per year, alcoholic dementia patients may regain 0.5 points per year with prolonged sobriety. Many patients have nutritional deficiencies that produce thiamin or folic acid deficiency state. Patients

with alcoholic related medical problems need careful medical attention to assure that heart or liver disease does not contribute to confusion.

Patients with alcohol induced dementia are at high risk for falls because of damage to nerves and cerebellum. Alcoholic patients are at high risks for subdural hematomas, i.e., collections of blood between the brain tissue and outer covering produced by trauma. Anytime an alcoholic patient sustains a fall and subsequent alteration of function or consciousness the patient should be examined for new neurological findings and the treatment team should consider the performance of a CAT scan to exclude a subdural hematoma. New drugs for Alzheimer's disease are not shown beneficial for patients with alcohol induced dementia.

Psychiatric problems produced by alcohol induced dementia are treated with appropriate psychotropic medications. Antidepressants or antipsychotics are more effective for alcohol-induced psychiatric problems. Apathy rarely responds to antidepressants or other psychotropic medications. Impulsive or hostile behavior can be managed with anticonvulsants, antipsychotics, or Lithium. Benzodiazepines can sometimes be use to manage irritability or anxiety.

Alcohol induced dementia is a common form of intellectual loss. Patients with alcoholic dementia frequently manifest behavioral as well as intellectual symptoms. Alcoholic dementia differs from Alzheimer's disease because many patients have discrete neurological abnormalities. Patients with alcohol induced dementia may improve over time if they maintain continuous sobriety.

Although some patients stabilize or improve with time, other patients demonstrate progressive cognitive loss. The cause of this ongoing intellectual decline is not understood. End of life care resembles that of other types of dementia.

FACTS ABOUT VASCULAR DEMENTIA FOR HOSPICE CARE

Vascular dementia (VaD) is defined as permanent cognitive impairment produced by vascular damage to the brain. Although old textbooks, i.e., prior to 1980, suggested that most dementia is produced by strokes, recent autopsy brain studies show that vascular dementia is a far less common, i.e., third or fourth cause of intellectual loss in people over the age of 65.

The diagnostic criteria for vascular dementia include: 1) documented intellectual loss, 2) extensive vascular damage to the brain, and 3) a relationship in time between the occurrence of strokes and the appearance of intellectual symptoms. The timing of the strokes should coincide with the onset or progression of cognitive decline. Strokes are frequently seen in the brains of patients with other types of dementia, such as Alzheimer's disease. Mixed dementia is intellectual loss produced by multiple disease processes in the same brain, e.g., Alzheimer's and vascular dementia or Alzheimer's and diffuse Lewy body disease. Mixed dementia is quite common; especially with vascular damage as one component.

The symptoms of vascular dementia cannot be definitively distinguished from Alzheimer's symptoms based on history or mental status examination. Vascular dementia patients may have a stair-step clinical course in which they demonstrate significant drops of function following vascular injury to the brain (**Table 1**). Patients with vascular dementia develop cognitive, e.g., amnesia, aphasia, agnosia, and apraxia, as well as psychiatric symptoms, e.g., hallucinations, delusions, and behavioral disturbances that are common to most other types of dementia. The VaD patient may experience more behavioral problems and depression than Alzheimer patients.

Table 1

Symptoms of VaD
<ul style="list-style-type: none">• Abrupt Onset• Fluctuating Course• History of Strokes• Focal Neurological Symptoms
<small>Dementia Other Than Alzheimer's</small>

The clinical findings in persons with vascular dementia may be distinct from Alzheimer's disease. A significant number of VaD patients demonstrate focal neurological deficits that are not typically present in the Alzheimer's patient. Frequently, these neurological findings are subtle, e.g., mild weakness on one side of the body, abnormal reflexes, etc. The VaD patient often demonstrates other evidence of cardiovascular disease, e.g., hypertension, past history of heart attacks, peripheral vascular disease, etc. Brain imaging studies, e.g., CT or MRI scans, may be helpful for documenting specific strokes or other types of vascular damage to the brain. Functional studies such as SPECT scans, i.e., Single Photon Emission Computed Tomography, may demonstrate a pattern of patchy abnormal brain function, i.e., hypoperfusion, that is distinct from Alzheimer's disease. There is no blood test or genetic screen for vascular dementia. Neuropsychological testing may help distinguish VaD from other types of dementia.

Vascular dementia is produced by cumulative vascular damage to the brain. No specific type, location, or size of stroke will predict intellectual decline. Observable vascular brain damage occurs in almost half of persons over the age of 65 and multiple different types of injury are present in many older persons (**Table**

2). The five major types of vascular brain damage include: 1) strokes produced by atherosclerosis, 2) hypertensive changes, 3) anoxic brain damage, 4) ischemic white matter damage, and 5) hypotensive brain damage (**Table 3**).

Table 2

ISCHEMIC BRAIN LESIONS IN OLDER PERSONS			
Pathology	n	Method	%
Any Infarct	5888 ¹	MR	36%
Lacunes	1086 ²	Autopsy	49%
Lacunes	1273 ³	CT	26%

1. Longitudinal Community Study; Radiology 1997, 202:47-54
 2. Japanese Neuropsychiatric Autopsy Series; Stroke 1991, 22:993-996
 3. Patients with past CVA's; Stroke 1991, 22:175-181

Dementia Other Than Alzheimer's

Table 3

Type and Location of Vascular Pathology Commonly Seen in Vascular Dementia	
<u>TYPE</u>	<u>LOCATION</u>
Embolic Infarcts	Cortex
Lacunar Infarcts	Basal Ganglia and thalamus
White Matter Ischemia	Periventricular
Anoxic Brain Damage	Hippocampus
Hypotensive	Watershed zones, hippocampus

Dementia Other Than Alzheimer's

A stroke is the death of a discrete segment of brain tissue produced by cessation of blood flow to that region. Most strokes are produced by atherosclerosis; a disorder of larger diameter blood vessels. Atherosclerosis, i.e., hardening of the arteries, is a common disorder that is present in most persons over the age of 65.

Hypertension, elevated lipids, and diabetes, are risk factors for atherosclerosis. Atherosclerosis damages the inner layer of a typical three-layer blood vessel and cholesterol debris is often deposited in the inner layer of large vessels. This bulging defect, i.e., atherosclerotic plaque, can produce a blood clot that occludes the blood vessel or fragments of debris from these deposits will break loose, travel down stream and produce a stroke by occluding a smaller diameter blood vessel. Most vascular dementia is produced by damage resulting from atherosclerosis (Table 4).

Severe heart disease can produce poor blood flow and blood clot formation, i.e., thrombus, within heart chambers, i.e., ventricles. Emboli, i.e., fragments of these clots, can circulate to the brain and produce a variety of strokes. Irregular beating, i.e., arrhythmias, such as atrial fibrillation will often produce embolic strokes.

Table 4

CAUSES: Vascular Dementia				
TYPE	BIOLOGY	LOCATION OF SOURCE	LOCATION OF INFARCT	SEQUELAE
Atherosclerosis	<ul style="list-style-type: none"> • Hypertension • Elevated lipids 	Intima of large diameter blood vessels	Cortex	<ul style="list-style-type: none"> • Occlusion of vessel • Embolization • Low flow state
Arteriolar sclerosis	Hypertension	Media of small arteries	Subcortical	<ul style="list-style-type: none"> • Occlusion • Micro-aneurysm with hemorrhage
Embolization	Atherosclerosis	Heart or extracranial blood vessel	Cortical	<ul style="list-style-type: none"> • Embolic occlusion of vessel
White Matter Ischemia	Hypertension	Small vessels	Periventricular	<ul style="list-style-type: none"> • Unclear
Hypoperfusion	Low Blood Pressure	Cardiovascular Dysfunction	Watershed Zone	<ul style="list-style-type: none"> • Pale or red infarcts

Arteriolar sclerosis is damage to small blood vessels produced by years of hypertension. Unlike atherosclerosis, hypertension will damage the middle layer of small caliber blood vessels. Hypertensive injury can progress to disintegration

of the blood vessel wall and bleeding into brain tissue. Arteriosclerosis can also result in blood vessel blockage that produces a small slit-like stroke referred to as a lacunar infarct. Hemorrhages or lacunes are common in persons with untreated hypertension and hemorrhage can lead to catastrophic damage or death.

The brain white matter contains fibers that connect neurons in each hemisphere or carry information to the spinal cord. The brain white matter is perfused by small penetrating blood vessels that travel long distances. These fragile blood vessels are susceptible to damage from high blood pressure and produce the “white matter abnormalities” that are commonly described in the brains of older patients. Multiple terms, e.g., Binswanger’s disease, subcortical arteriolar sclerotic leukoencephalopathy, and leukoariosis, are used to describe the white matter pathology. The relationship between white matter damage and dementia is unclear, although these patients are at higher risks for developing depression.

Low oxygen or low blood flow to the brain produces anoxic brain damage. Neurons can only survive for three minutes without adequate oxygen or blood flow, e.g., persons who sustain a cardiac or respiratory arrest. Certain cardiac arrhythmias, i.e., irregularity of heart beat rhythm are associated with intellectual deficits. Atrial fibrillation is a common arrhythmia in the elderly that predisposes to strokes and intellectual decline. Vulnerable brain regions like the hippocampus are very sensitive to low oxygen and damage to this region produces amnesia. Many older patients who undergo cardiac bypass surgery will experience temporary or permanent intellectual deficits.

The treatment for vascular dementia is prevention. Most vascular damage to the brain can be avoided through control of blood pressure, lipids, heart disease, obesity, diabetes, smoking cessation, and regulation of heart rhythm. The medications presently available for Alzheimer’s disease are not effective for patients with vascular dementia. The standard behavioral management strategies

used for Alzheimer patients are appropriate for patients with vascular dementia. The treatment of psychiatric symptoms with psychotropic medication is similar to other dementias. The family caregiver of a vascular dementia patient requires the same support as any other dementia patient caregiver.

The natural history of vascular dementia may be more aggressive than Alzheimer's disease with two-thirds or three-quarters of VaD patients dead or institutionalized at five years. The VaD patients may demonstrate more psychiatric disability, e.g., depression. Control of cardiovascular disease, hypertension, or surgical repair of damaged blood vessels may improve patient outcomes (**Table 5**).

Vascular dementia can be distinguished from other dementias through careful attention to clinical history and neurological examination. The clinical presentation of VaD may differ from AD because VaD patients may have stairstep progression, focal neurological deficits, and vascular damage on brain imaging (**Table 6**). The Lewy body patient frequently presents with early hallucinations while the VaD patient usually demonstrates intellectual decline. The Lewy body patient has extrapyramidal symptoms while the vascular patient has focal neurological deficits. Alzheimer's and frontal dementias rarely manifest focal neurological signs or evidence of extensive strokes on brain imaging.

Table 5

Natural History at 5 Years for Vascular Dementia	
• 6.4%	Improved
• 43%	Died
• 21%	Remained Independent
• 29%	Required Long-term Care

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In conclusion, multiple different types of vascular damage to the brain produce vascular dementia. The clinical history of VaD can resemble Alzheimer's disease; however, the vascular dementia patient is more likely to have focal neurological

HOSPICE MANUAL 49

deficits. Brain imaging may help to distinguish these two diseases. The treatment for vascular dementia is prevention and the natural history may be more aggressive than Alzheimer’s disease (Table 6).

The life expectancy for vascular dementia is similar to that of Alzheimer’s disease. End of life management is similar to that of other dementias.

Table 6

Common, Important, Early Manifestation of Dementia Patients Identified by a Basic Evaluation					
TYPE	EARLY COGNITIVE LOSS	EARLY PSYCHIATRIC SYMPTOMS	MEDICAL	NEUROLOGICAL	LABORATORY
Alzheimer’s	Moderate Amnesia	Mild anxiety, depression	None	None	None
Vascular	Moderate	Moderate • Depression • Psychosis	Hypertension Cardiovascular Disease	Focal Deficits	Strokes on CT
Alcoholic	Mild	Moderate Apathy	Heart, liver, pancreas, nerve	Ataxis, Sensory Loss	Abnormal: liver, blood, indices
Diffuse Lewy Body	• Moderate • Fluctuating	• Moderate visual hallucinations • Fluctuating	None	Parkinsonism	None
Frontotemporal Dementia	Mild	Moderate Apathy	None	None	None

Any kind of dementia can produce any combination of symptoms. Some patients have mixed dementia.

MANAGEMENT OF PAIN IN PERSONS WITH DEMENTIA

Pain is a common medical condition in older persons; especially residents in long term care (LTC) settings. Pain is defined as a sensory and emotional experience associated with actual or potential tissue damage. Chronic persistent pain occurs in 24% of LTC residents while only 29% are free of all pain. Most, i.e., 74%, demented nursing home residents have some pain and the majority, i.e., 70%, are untreated or under-treated. Pain can have multiple origins; however, discomfort produced by musculoskeletal disease is the most common problem in the older person, e.g., arthritis 42%, bone fracture 12%. Untreated or under-treated pain can produce significant suffering as well as agitation and behavioral problems in persons with dementia. Regular administration of acetaminophen can reduce agitation in more than one-half of agitated, demented patients with pain. Assessment and management of pain is an important responsibility of any clinical management team. Dementia patients are less likely to receive analgesics despite the fact that they experience suffering equal to cognitively intact individuals.

Neuroanatomy of Chronic Pain

The therapy for pain should target each level within the nervous system that produces the noxious sensory stimulus. The brain perceives pain via a complex series of emotional and intellectual responses to pathways that begin at the level of the pain-sensing organ and end with our interpretation of the sensory stimulus (**See Table 11-3**). Pain sensors are located throughout the skin, joints, bones, and organs within the body. The pain associated with a burn, bruise, or broken bone is perceived through specialized nerve endings in each tissue. The sensory nerve impulse is transmitted to the spinal cord via peripheral nerves. The spinal cord receives the raw information and transmits the sensation to a relay station in the base of the brain termed the thalamus where the information is organized. The thalamic neurons then relay the organized information to the brain region that

integrates sensory information called the parietal lobe. The parietal lobe recruits limbic systems to judge the level of distress and develop an emotional response to this discomfort, e.g., temporal and frontal lobes. Malfunction at any level in the pain circuit can produce misinterpretation of painful or noxious stimuli. Visceral sensations from bladder, bowel, stomach, gallbladder, etc. are transmitted to a distinct brain region buried beneath the temporal lobe called the insular cortex. Alzheimer's disease does not damage sensory pathways from the body and internal organs; however, brain regions that interpret these messages are altered by the disease. Stimulation or damage at each sensory processing level can produce specific pain syndromes that require distinct therapeutic interventions. The interpretation of pain in dementia patients is complicated because they misidentify, under-recognize, over report, or ignore painful stimuli due to damaged cortical centers that integrate sensory information, i.e., parietal lobe, insular cortex. The normal intellectual expressions of pain, such as verbal complaints or help-seeking are replaced by agitation, hostility, and aggression.

Pain Assessment in Dementia

The assessment of pain in the demented patient requires a review of medical records to determine the timing and sequence of the painful experience as well as a careful physical examination. Demented patients require a mental status examination to determine their ability to interpret pain, or ask for medication, as well as exclude depression or anxiety that might intensify the painful sensation. Chronic pain can produce depression and many patients experience less discomfort when treated with antidepressants. Tricyclic antidepressants like Elavil are helpful in younger patients but this medication causes severe confusion in demented patients. Other TCAs with fewer side effects, e.g., desipramine, nortriptyline, are as effective as Elavil at equivalent doses.

Recognition of pain in demented patients usually requires direct observation as these individuals frequently suffer from receptive and expressive aphasia. Tense body language, sad facial expressions, fidgetiness, loud perseverative verbal outbursts and immobilization of specific body parts may indicate pain. Facial expressions that include clenched teeth, widely opened eyes, or tightly shut eyes may suggest the patient is experiencing significant pain. Distress or agitation during attempts at repositioning, transfer, or ambulation may indicate unrecognized arthritic or orthopedic pain. Episodic pain with secondary diaphoresis may indicate angina. Some verbal outbursts may result from chronic, untreated or under-treated pain. The frequency and intensity of these pain symptoms must be documented in the record. Pain charts are often helpful.

Management of Acute and Chronic Pain in Dementia

The first step in pain management is assessment of the discomfort. Acute pain syndromes commonly follow injuries, surgical procedures, etc. and require standard analgesic or narcotic management. Acute pain syndromes are expected to last for brief periods of time, i.e., less than six months. Pain that persists for over six months is termed chronic pain. Chronic non-malignant pain requires a more complex strategy to minimize the use of narcotics and maximize non-pharmacological interventions. Acute pain rarely produces other long-term psychological problems, such as depression, although acute discomfort will produce distress manifested by acute anxiety or agitation in the demented patient. Mildly demented patients can become agitated or anxious with pain because they rapidly forget explanations or reassurances provided by staff. Amnesic individuals may forget to ask for PRN non-narcotic analgesics such as acetaminophen and these patients need regularly scheduled medications. Disoriented patients do not realize they are in a health care facility and aphasic patients may not comprehend the staff's inquiry about pain symptoms.

The symptoms of pain expressed by patients with moderate to severe dementia include anxiety, agitation, screaming, hostility, wandering, aggression, failure to eat, and failure to get out of bed. A small number of demented individuals with serious injury may not complain of pain, e.g., hip fractures, ruptured appendix, etc. Assessment of pain in the demented patient requires verbal questioning and direct observation to assess for behaviors that suggest pain. Standardized pain assessment scales should be used for all patients; however, these clinical instruments may not be valid in persons with dementia or psychosis. The past medical history may be valuable in assessing the demented resident. Individuals with chronic pain prior to the onset of dementia usually experience similar pain when demented, e.g., compression fractures, angina, neuropathy, etc. These individuals can be monitored carefully and non-narcotic pain medication can be prescribed as indicated, e.g., acetaminophen on a regular basis, anticonvulsants for neuropathy.

Management of Chronic Pain

The management of pain in any person requires careful consideration about the contribution of each component of the pain circuit to the painful stimulus (**See Table 3**). Neuropathic pain is produced by dysfunction of the nerve or sensory organ that perceives and transmits noxious stimulus to the level of the spinal cord. Radicular pain, i.e., pain occurring in a specific nerve pattern, is more consistent with dysfunction of a specific nerve, e.g., sciatica that radiates down the back of the leg. Persons with serious back disease may have herniated discs that compress specific nerve roots. This pain is often positional and produces spasms of the musculature in the back.

Damage to the spinal cord can produce chronic, neuropathic or non-localizing pain. This discomfort is commonly seen in persons with traumatic back injuries. Strokes in the thalamus can produce a chronic pain syndrome called thalamic pain by misinforming the brain that a painful stimulus has been received.

The brain interprets pain in a highly organized systematic pattern. Discrete brain regions interpret and translate painful stimuli from specific body regions, e.g., arm, leg, etc., misfire in that discrete brain region will misinform the person that pain or discomfort is being experienced in that limb or part of the trunk. A person who loses a limb from trauma or amputation may continue to experience painful sensations in the distributions for that limb termed *phantom limb pain*.

Management of chronic pain involves three elements (1) physical interventions, (2) psychological interventions, (3) pharmacological interventions. Physical interventions include basic physiotherapy that incorporates warm or cool compresses, massage, repositioning, electrical stimulation and many other treatments. Dementia patients need constant reminders to comply with physical treatments e.g., using compresses, sustaining proper positioning, etc., and many do not cooperate with some interventions, like nerve stimulators or acupuncture. Physical interventions are particularly helpful in older persons with musculoskeletal pain regardless of cognitive status. Psychological interventions usually require intact cognitive function e.g., relaxation therapy, self-hypnosis, etc. Demented patients generally lack the capacity to utilize psychological interventions; however, management teams should provide emotional support to validate the patient's suffering associated with pain. Demented patients may experience more suffering from pain than intellectually intact individuals because they lack the capacity to understand the cause of their discomfort. Fear, anxiety, and depression frequently intensify pain.

Pharmacological management begins with the least toxic medications and follows a slow progressive titration until pain symptoms are controlled. Clinicians must distinguish between analgesia and euphoria. Some medications that appear to have an analgesic or pain relieving effect actually have a euphoric effect, which

diminishes the patients' concern about perceived pain. The goal of pain management is to remove the suffering associated with the painful stimulus rather than making the patient euphoric or high to the point where they no longer care whether they experience pain. Euphoria-producing medications can cause confusion, irritability, and behavioral lability in patients with dementia. Narcotic addiction is not a common concern in dementia patients as these individuals have a limited life expectancy and rarely demonstrate drug-seeking behaviors.

Pharmacological interventions always begin with the least toxic, i.e., least confusing, medications. A regular dose of acetaminophen up to 4 grams per day will substantially diminish most pain and improve quality of life. Clinical studies show that regular Tylenol reduced agitation in over half the treated patients. Chronic arthritic pain with inflammation of the joints may also respond to non-steroidal anti-inflammatories (NSAIDs) or Cox-2 inhibitors. The gastrointestinal toxicity associated with NSAIDs is greater than that of Cox 2 inhibitor medications. Patients who fail to respond to non-narcotic analgesics should receive narcotic-like medications, i.e., tramadol. Patients who fail to respond to maximum doses of tramadol, i.e., 300 mgs per day, may require narcotic medications.

Calcitonin is effective in some chronic pain associated with osteoporosis and fractures. Osteoporotic fractures are common painful complications of aging and produce significant distress in demented and non-demented individuals. Studies demonstrated that 50 to 100 units of nasal calcitonin would substantially reduce discomfort associated with fractures. Calcitonin suppositories were also effective for treatment of long-term bone related pain.

OPIATE MANAGEMENT OF THE DEMENTED RESIDENT

The prescription of opiates for dementia patients requires attention to the need to relieve distress caused by pain and the potential for medication toxicity. The World Health Organization has proposed a three-step analgesic ladder for use in pain caused by cancer, which may be a useful guide in patients with dementia, as well. Pain treatment starts with non-narcotic medications, and moves up the ladder as indicated by patient response and tolerability of therapies. At any step in the ladder, co-prescription of non-opiate analgesics (acetaminophen, NSAIDS, COX-2 inhibitors), as tolerated, can provide synergistic relief and reduce the doses of opiate necessary for good pain control.

The choice of specific opiate compounds depends on the situation. For intermittent pain, short-acting immediate release opiates may be sufficient (Step 2 on the WHO ladder). Many of these are available in preparations combined with acetaminophen or an NSAID. Codeine preparations provide a relatively mild analgesic effect, but can be as “constipating” as stronger narcotics. Preparations containing meperidine, pentazocine, and propoxyphene can worsen confusion in dementia patients and should generally be avoided in this population. Mixed agonist-antagonist medications (e.g., butorphanol, nalbuphine, pentazocine) are problematic for use in this setting, particularly if the patient has been exposed to other opiates. Hydrocodone, morphine, and oxycodone preparations are preferred for pain requiring intermittent or short-term opiate treatment.

Severe pain that is refractory to less aggressive measures can be treated with WHO Step 3 agents such as fentanyl, hydromorphone, morphine, or oxycodone. Patients with persistent severe pain require continuous dosing around-the-clock to avoid breakthrough pain. To avoid every 2 to 4 hour dosing around the clock, sustained release preparations are used once the patient’s 24-hour dose need is determined

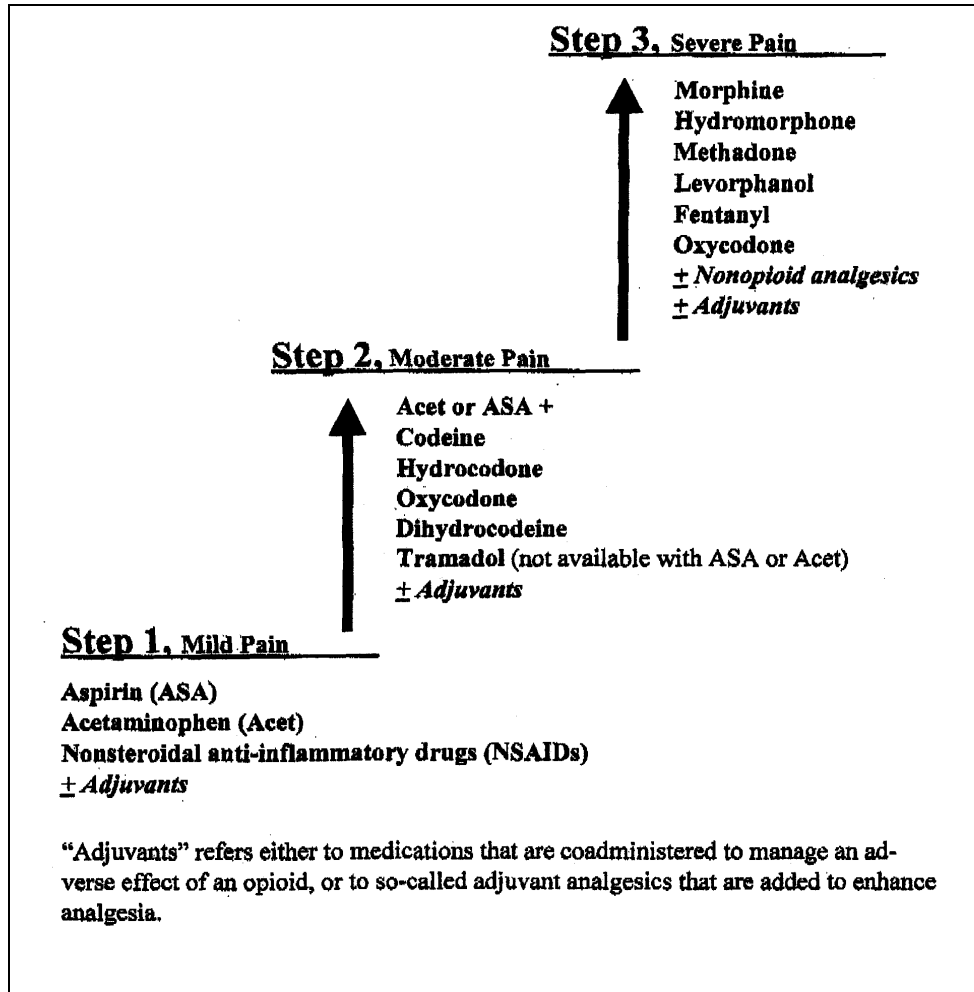
using immediate-release preparations. Breakthrough (or rescue) doses should also be provided as a PRN; a dose of an immediate-release preparation available every 2-4 hours PRN is ideal for breakthrough dosing. A breakthrough dose of 10% of the total 24-hour sustained-release dose is a good rule of thumb. If more than one or two breakthrough doses are needed on a regular basis, the sustained-release dose should be adjusted. The goal of opiate therapy for severe pain is to control as much of the pain as possible with the sustained-release medication. Common side effects of opiate therapy include constipation, dry mouth, nausea, and sedation. Constipation is sufficiently common in elderly patients with dementia and prophylactic treatment (e.g., stool softeners) is indicated when opiate therapy is initiated. Bowel function should be closely monitored while on opiate therapy to avoid impaction that may produce agitation or diminished oral intake.

Chronic analgesic therapy should be continued in severely demented patients unless re-evaluation shows resolution of pain. Severely aphasic patients must be carefully observed for non-verbal expression of pain after discontinuation of medication. A slow taper off opiates is indicated to avoid withdrawal symptoms in tolerant patients and to allow monitoring for re-emergence of pain.

Dose conversion tables (examples attached) can be used to convert from one opiate to another (if the first agent is poorly tolerated) or to calculate an appropriate breakthrough dose of an immediate-release preparation for sustained-release agents without an immediate-release form (e.g., fentanyl).

Table 1

WHO 3-Step Ladder



In 1986, the World Health Organization (WHO) developed a 3-step conceptual model to guide the management of cancer pain. It provides a simple, well-tested approach for the rational selection, administration, and titration of a myriad of analgesics. Today, there is worldwide consensus favoring its use for the medical management of all pain associated with serious illness.

Table 2

NARCOTIC DOSING RANGES AND EQUIVALENT DOSES

STANDARD GERIATRIC DOSE		EQUINANALGESIC DOSES OF OPIOID ANALGESICS		
ANALGESIC	DOSE RANGE (MG)	ORAL/RECTAL DOSE (MG)	ANALGESIC	PARENTERAL DOSE (MG)
Codeine	15-60mgm PO q4-6hrs	100	Codeine	60
Hydrocodone	2.5-5mgm PO q4-6hrs	15	Hydrocodone	-----
Hydromorphone	1-2mgm PO q4-6hrs	4	Hydromorphone	1.5
Oxycodone	2.5-5mgm PO q6hrs	10	Oxycodone	-----
Levorphanol	2-3mgm PO q12hrs	2	Levorphanol	1
Methadone	2.5mgm PO q8-12hrs	10	Methadone	5
Morphine	10-30mgm PO q4hrs	15	Morphine	5
Fentanyl	SEE PDR	-----	Fentanyl	0.1

This table demonstrates routine dosing ranges and equivalent doses among the commonly prescribed narcotic.

Data from Geriatric Dosage Handbook.

Table 3

CORRELATING THE ANATOMY OF PAIN TO THERAPY

The Pain System in Dementia				
Neurological Level Generating Pain Signal	Function of Level	Classic Symptoms of Dysfunction	Change by Dementia AD or Other	First Line Therapy (When level is damaged)
Pain receptors Sensory nerves	Receive and Relay Pain	Diminished sensation or burning, painful sensation *Neuropathic pain	AD – No change ETOH- ↑ or ↓	Anticonvulsants
Spinal Cord	Relay individual pain signals	Neuropathic or visceral	None	Anticonvulsants
Thalamus	Collect and relay pain signals	↑ or ↓ pain *Thalamic pain syndrome *Phantom limb pain	Unclear	Anticonvulsants for thalamic or phantom limb pain
Parietal and Insular Cortex	Localize and interpret pain message	↑ or ↓ pain *Phantom limb pain	↓ Ability to recognize by all dementia	*Analgesics *Other meds appropriate to pain source
Limbic System	Reaction to Pain	Distress, agitation, hostility, apathy, depression	↑ or ↓	*Analgesics *Mood stabilizers *Behavior mgt.