

CHAPTER THREE

DEMENTIA

A Special Kind of Caring

Overview:

Dementia is a term used to describe a group of symptoms characterized by:

- short and long term memory deficit,
- impairment in abstract thinking,
- impairment of judgment,
- impairment in communication skills,
- changes in personality,
- changes in mobility, and
- changes in behavior.

No two persons experience the symptoms or disease progression in the same manner. Dementia, *a brain disease*, will eventually interfere with daily functioning in all aspects of life.

Ultimately, living with a diagnosis of dementia is a frustrating experience not only for the person experiencing the symptoms but also for the family caring for the person with dementia.

The Brain:

The body is a finely tuned instrument where all systems work well together to produce and support good health. The brain, a “supercomputer”, is the seat of all body functions such as memory, moods, sensory perceptions, walking, breathing, blood circulation, pain, abstract thinking, identity, just to name a few. When a person has *a brain disease*, many of these functions become altered or destroyed. The area of the brain affected is directly related to the symptoms manifested by the person.

Types of Dementia:

There are two categories of dementia – reversible and non-reversible.

There are medical conditions in which the person can present with symptoms that mimic dementia. Some of these conditions are brain tumors, metabolic changes, nutritional deficiencies, head trauma, medications, and depression. Delirium is another reversible illness which presents with acute mental confusion triggered by infections such as urinary tract infection or pneumonia. The person with delirium may display drowsiness, restlessness, confusion, lack of awareness of person, place or time, and forgetfulness.

With proper evaluation and treatment of the acute illness or condition, the confusion and other symptoms related to delirium have the potential to be reversed.

The non-reversible causes of dementia are basically a result of degenerative type diseases.

Disease	Age of Onset	Characteristics
Pick's Disease	Young adult	-Wasting of the brain resulting in disturbances in behavior, personality and eventually memory
Lewy body type		-Course unpredictable characterized by the presence of protein deposits in the nerve cells; -May experience complex visual hallucinations; -The person may get lost easily; -Affects ability to think, memory, language, judgment and reasoning
Parkinson's Disease	Generally after age 50	This disease affects that portion of the brain which controls movement and is characterized are shaking, difficulty with movement including walking, and coordination; -Dementia appears in the late stage of Parkinson's Disease
Huntington's Chorea	Onset 35 to 50	-This is an inherited disease causing a wasting of the nerve cells in the brain. -Symptoms manifested are personality changes, progressive loss of mental function, and loss of cognitive functions such as speech, calculation skills, and judgment
Vascular Dementia		-Generally results from small strokes within the brain; -Onset is abrupt with such symptoms as paralysis, difficulties with language and vision loss.
Alzheimer's Disease	Early onset - before age 60 Late onset - age 60 or older	-Most common of the dementias; -A thorough medical examination needs to be done to rule out other causes for dementia. -Definitive diagnosis can only be made during autopsy; -There are structural changes within the brain called plaques and tangles as well as an alteration in brain chemicals; -Persons with Alzheimer's disease will experience a reduction in memory and functional ability over time until the person can no longer care for self.

Diagnosis:

When you or someone you love is experiencing what you believe to be the symptoms of dementia, it is crucial to seek a thorough medical evaluation. You can assist the physician by keeping a pre-visit diary noting specific examples of your concerns. Items to describe in detail are:

1. onset of the symptoms,
2. pattern or frequency of symptoms such as time of day, frequency of occurrence (daily, hourly, intermittent),
3. anything that precipitates the symptoms,
4. anything that will alter or stop the symptoms,
5. changes in memory,
6. specific behaviors such as hitting, screaming, pacing, etc. and related triggers that initiate these behaviors such as loud noises, weather, repetitive patterns, etc.,
7. issues related to personal care,
8. issues related to home safety especially in the kitchen and bathroom, and
9. issues related to driving especially getting lost, control of car, change in driving habits

During the physician's visit, you can expect to share the information in the diary known as a history of the symptoms. A complete medical history will be taken, and a physical examination will be given which includes a variety of blood work to rule out any acute medical problem which can be appropriately treated. A neurological examination, psychological examination and mental status examination will also be completed. These examinations will be completed by the person's physician or a referral may be made to a neurologist, a psychologist or psychiatrist.

Family members should be aware that while doing the mental status examination, the physician will request that only the person with the symptoms be in the room while being tested. During the mental status examination, the person will be asked a series of questions which will test memory, reasoning ability, visual-motor coordination, language skills, knowledge of time / person / place.

Because of the advances in medical and research technologies, various scans may now be able to assist with the early diagnosis of a dementia.

There will be times when the actual diagnosis can be made only at the time of death through autopsy. However, because of advances in research, ongoing evaluations of the person, the tracking of the progression of symptoms, physicians can now be rather confident of the diagnosis.

Treatment:

For the reversible dementias, physicians can treat the cause of the disease.

For the non-reversible dementias, there generally are no known treatments that will cure the disease. However medications, treatments, and therapies are available which may slow down the progression of the dementia. For the most up to date information on medications and treatments for dementia, confer with your physician, pharmacist, or related disease specific association such as The Alzheimer's Association.

Managing a person with a dementia:

Without specific treatments to cure a dementia, the best approach is to manage the disease based on the person's symptoms and ability to function within their specific environment. It is best to allow the person to remain in a familiar environment such as their own home. Safety for the person with a diagnosis of dementia should be a primary focus. Consider areas and issues related to the kitchen, bathroom, use of throw rugs, driving the car, lighting within the home, clutter and a lack of color contrast. An example of the latter may be in the bathroom which has white floors, white walls, and a white toilet. Being all white, the person with dementia may not be able to tell the true location of the toilet and thus experience a fall.

Patience on the part of the spouse or caregiver, though always a challenge, is very important. As the dementia progresses, the person with dementia may need slower and more specific step by step instructions. Activities should promote confidence and self esteem. Remember, dementia is a brain disease so arguing or trying to change the person's mind will not be a benefit to the person with dementia or the caregiver. The caregiver must meet the person with dementia at their level of functioning.

Options beyond home

When family, physician, and other support systems need additional assistance on a full-or-part-time basis, there are several options available to them for care.

Adult day care centers are available on full- or part-time basis to allow individuals with dementia to engage in fulfilling activities and socialize with others. In addition, this time allows family caregivers to continue to work, run errands or have some time for themselves. Depending upon the center, the following services may be provided – personal care, meals, transportation, medication administration and appropriate socialization and activities. The frequency of services provided can range from once a week to daily with the hours being flexible. Generally, services are provided on a fee for service though in some communities there may be some form of reimbursement.

Respite care can be provided either in an assisted living facility or a health care center for a period of time which is mutually agreed upon by the family and facility. This type of care is to give families the ability to go on vacation or just to have a break from care

giving responsibilities and know that their loved one is well cared for. Depending on the level of functioning of the individual, the respite care may be provided in a secure unit. The person admitted for respite care must abide by the guidelines of the facility. Reimbursement is a fee for service and generally there is no other financial assistance.

Assisted Living Facilities provide various levels of care to individuals with dementia. Those with mild forms of the disease may function well with the additional structure of activities and socialization that an assisted living facility provides. As the individual's functioning and memory declines, the services provided ensure that the individual receives appropriate personal care and medical coordination. Some assisted living facilities have secured dementia units when additional monitoring, supervision and care is required.

Health care centers also provide care to individuals with dementia, as well as other services previously mentioned in this manual. Centers may have secured units for individuals with dementia or may provide programming for individuals within the general facility. Secure units are locked to provide a safe and secure place for those who may have a tendency to wander or display inappropriate behaviors. The goal of a secure unit is not only to provide a safe environment but also to provide programs and activities which will enhance the life of the individual. It should be noted that some facilities will discharge persons from a secure unit when the person no longer benefits from the programs or the behaviors are controlled.

Selecting a facility may not be an easy decision. Assistance may be available from the local Office of Aging or just taking time to visit facilities. It is recommended that more than one visit be made at various time of the day. Considerations when selecting a facility may be, but are not limited to:

1. location near family,
2. facility licensure and results of annual state surveys,
3. special programming for persons with dementia,
4. availability of a special unit for persons with dementia,
5. care is person centered,
6. staff training related to care of a person with dementia,
7. environment – are residents surrounded by familiar items, odor free, pleasant staff, safety, accessibility to the outdoors,
8. staff honor food preferences and modify it as the person's condition declines,
9. visiting hours,
10. staffing levels and
11. family participation in care.

Reimbursement: Many times, care for the person with a dementia is on a private, fee for service basis. In some communities financial resources may be available through special grants, Medicaid, long term care insurance though each policy is different, and office of aging subsidy.

Prevention:

Unfortunately, there are no specific interventions to prevent dementia. The best that one can do is to live a healthy life style as there is evidence that this can be of some help. Be mindful of good nutrition, exercise, spiritual health, mental stimulation, and participation in social activities.

Care for the caregiver:

Caring for a person with dementia could last a long time – 10 years or more. Therefore it is imperative that the caregiver takes care of themselves as well. Refer to Ten Tips for Family Caregivers.

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Where To Turn For Help:

LEVELS OF CARE

Depending on the level of impairment, individuals with dementia can be cared for in almost all of the settings previously mentioned in this manual. In addition, an increasing number of skilled nursing and assisted living facilities have specialized living units catering to the unique needs of residents with Alzheimer’s and related dementia.

Links to

www.greenridgevillage.org; www.eastonhome.org; www.kirklandvillage.org;
www.wmvallentown.org; www.forestparkhealth.org; www.sycamoremanor.org;
www.warepresbyterian.org

Home Health Care

Home health care services range from the delivery of a hot meal once a day to 24-hour, in-home nursing care. If it is the desire of the person to remain at home and the principal caregiver can support this decision financially, this may be a viable option.

Respite Care

Many skilled nursing and assisted living facilities offer “respite” care for people with Alzheimer’s. The stay is limited (a few days to a month) at the facility. For caregivers, this service can be a wonderful break.

Adult Day Care

Depending on the facility, a caregiver may be able to use “drop-in” services or full-time day care. Participants are involved in daily activities and are fed and cared for while the caregiver is running errands or at work.

Assisted Living

Many assisted living facilities also provide respite services for caregivers. This living situation is suitable for a person who does not need constant skilled nursing assistance, but does need help with one or two of the “activities of daily living” (e.g. dressing, brushing teeth, etc.). Residents also may need medical assistance (e.g. have an IV, need to be turned or positioned, etc.).

Skilled Nursing Center

For those who need help with three or more activities of daily living (e.g. eating, toileting, dressing), a skilled nursing center is appropriate. An increasing number of facilities are designing Alzheimer’s units tailored specifically for the Alzheimer’s patient. (For more information, please see “Today’s Alzheimer’s Unit” on the following page.)