

Steps for a better Life

HANDBOOK FOR CAREGIVERS OF PERSONS WITH DEMENTIA



Steps for a better Life

Development of New Care Approaches for Alzheimer's Family Caregivers (DemCARE)

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Table 1 Consortium Partner List

No	Name	Short Name	Country
1	BURDUR GOVERNORSHIP (COORDINATOR)		Turkey
2	SOCIAL INCLUSION AND EDUCATION ASSOCIATION	BUHAYAD	Turkey
3	BURDUR PROVINCIAL DIRECTORATE OF HEALTH		Turkey
4	SLOVENSKO ZDRUŽENJE ZA POMOČ PRI DEMENCI - SPOMINČICA ALZHEIMER SLOVENIJA	SPO	Slovenija
5	UNIVERSIDAD DE OVIEDO		Spain
6	ASSOCIAÇÃO PORTUGUESA DE FAMILIARES E AMIGOS DOS DOENTES DE ALZHEIMER		Portugal

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Acronyms and Abbreviations

Acronym/Abbreviation	Description
AD	Alzheimer`s disease or other form of dementia
IADL	Instrumental Daily Activities
GDS	Global Deterioration Scale
ICT	Information and Communications Technology

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1 Introduction

Dementia is the leading cause of disability worldwide, with an estimated 50 million people living with Dementia nowadays. It is expected that this number will triple by 2050, according to World Alzheimer Report 2018. If we take into account that Dementia does not affect only the Person living with Dementia (PwD), but it also directly affects the household as a whole, we can affirm that the number of people living with the reality associated with Dementia is certainly much greater than the number estimated.

The reality associated with Dementia is characterized not only by progressive changes in cognitive, social and emotional capacities, but also in the functionality of the Person living with Dementia, that is, in their ability to independently carry out the different Activities of Daily Living (Ex: personal hygiene, dressing, food, self-care and mobility).

Bearing in mind its progressive nature, the challenges associated with the disease itself, but also with the act of caring, are constantly changing, so it is necessary to provide direct support to the person with Dementia, with the aim of promoting the maintenance of their remnant capacities, for a maximum of possible time, as well as their caregivers, in order to be able to integrate the challenges inherent in the act of caring, especially for someone who is close to the family.

Faced with these issues, projects specially designed to train caregivers with the tools needed to cope with this situation are increasingly needed, capable of enabling the use of new digital tools, involving both the Person with Dementia and their caregivers. And it is essential that they promote not only exercises that enable cognitive stimulation, but also moments of well-being between the dyad.

The DemCARE project focuses on delivering assistance to family caregivers, as well as supporting a dignified life for people with dementia, providing information for person-centred care, adjusted for the changes that will occur throughout the disease, providing the best strategies for each situation. Through the development of an innovative training curriculum and interactive technologies, that support caregiving through playing, the DemCARE Project has a wide range of partners, with various areas of expertise, in order to contribute to the ultimate purpose of providing a better quality of life to the Person with Dementia and their caregivers.

2 Unit 1: What is Dementia?

Dementia refers to a clinical syndrome but the word 'dementia' is often misrepresented in loss of memory. The term dementia derives from the Latin root, which means being out of one's mind. Dementia is usually chronic and progressive nature disease that leads to deterioration in cognitive functions including the domains of memory, language, thinking, and orientation, ability to learn new information, planning the future, attention, problem solving and judgement (Gürvit, 2020).

2.1 Differences between normal and pathological aging. Risk and prevention factors

Dementia is not a part of normal aging, it is a consequence of brain disease. Considering forgetfulness as a natural part of aging sometimes delays the period from the onset of symptoms to the diagnosis of dementia and it cannot stop or reverse the disease. The expected "normal" decline with aging in some cognitive abilities, including memory, corresponds to age-adjusted levels of performance on neuropsychological tests. It is abnormal for an elderly person indicating social wellbeing to forget the names or have difficulty keeping track of their belongings. Family members start to suspect dementia following repetitive questions. Having memory loss that disrupts the daily life or getting lost in familiar places is not a normal sign of aging. People showing age-associated memory-related impairment symptoms is completely independent in their daily life. Normal range is expected in healthy ageing for these people in neuropsychological test performance especially for recent memory tests. Many people worry about becoming forgetful. They think forgetfulness is the first sign of Alzheimer's disease. But not all people with memory problems have Alzheimer's. Emotional problems, such as stress, anxiety, or depression, can make a person more forgetful and can be mistaken for dementia. For instance, someone who is coping with the death of a spouse, relative, or friend may have emotional problems that can cause forgetfulness but they can get better with social support. Dementia is chronic diseases with progressive deterioration of cognition, function, and behavior leading to severe difficulty completing daily tasks (Gürvit, 2020).

As in many diseases, risk factors in AD are divided into two as modifiable and non-modifiable risk factors. Non-modifiable risk factors are age and sex. Modifiable risk factors are treatable medical conditions and life style. These are later life (65+), being female, family history (dementia, Parkinson's, motor neuron disease, depression, psychosis, alcoholism), family history of Down Syndrome, low education, history of head trauma, cardiovascular and cerebrovascular diseases (hypertension, ischemic heart disease, high cholesterol levels, obesity, stroke), diabetes, endocrine-metabolic disorders (Vitamin D, B6, B12, folic acid deficiencies, hypo-hyperglycemia, hypothyroidism, electrolyte disorders), chronic infectious-autoimmune-inflammatory diseases (Systemic Lupus Erythematosus, Rheumatoid arthritis, Behçet's disease, syphilis...), depression, inactive life and unhealthy eating habits, cigarette smoking, excessive alcohol consumption and sleep disturbance. Electro-magnetic field exposure is also another risk factor for dementia. Electricians, repairmen, switchboard operators, technicians, welders, carpenters, tailors are at risk for exposure to extreme low frequency electromagnetic fields. Modifiable risk factors may be comorbid conditions that complicate dementia and that can be controlled (Gürvit & Yıldırım, 2020).

The Mediterranean diet, a diet rich in grains, vegetables, fruits, cheese, milk, especially fish, olive oil, and red wine, is a protective factor against dementia. Mental and physical activities delay cognitive decline in older persons with dementia. It has been shown that an average of one year regular exercise program not only stops the brain hippocampus loss, but also increases it by 2%. Numerous studies have revealed that older people who

engage in mental activities such as reading, doing artistic activities, playing games have a lower risk of developing Alzheimer's disease. It can be assumed that cholesterol-lowering drugs, antihypertensives and antidiabetics may be protective against dementia through the control of vascular risk factors (Gürvit & Yıldırım, 2020).

2.2 Before dementia - Mild Cognitive Impairment (MCI)

Memory loss is often one of the early signs of the condition. The dementia disease has an insidious onset and slow progression reaching the stage of dementia after about twenty years however there is a pre-clinical stage before a pre-dementia clinical stage. The patient and a close relative cannot give clear information about when the first complaints have started. Amyloid accumulation and changes in brain cells may continue in the preclinical period however, memory problems are not evident yet. In mild cognitive impairment stage, there are more problems with memory however, it is seen that these problems do not adversely affect the independence of the person yet. In other words, the patient's functionality does not deteriorate. Mild cognitive impairment may increase your risk of later developing dementia caused by Alzheimer's disease or other neurological conditions. But some people with mild cognitive impairment never get worse. Memory loss, difficulty in finding the right words, visual-spatial disorders impair a person's ability to function independently.

When the functionality has been impaired, we can talk about the stage of AD dementia (AHD), which is divided into mild, moderate and severe sub-stages. Until this stage is referred as ("mild cognitive impairment" – MCI) or prodromal AD. Alzheimer's disease pathology accumulates years before the onset of clinical symptoms and has been termed 'preclinical dementia'. In order to be characterized as Subjective Cognitive Impairment, the person must have cognitive/behavioral deterioration compared to his/her normal, this deterioration should not affect daily life activities, and his/her performance in neuropsychological tests should be within the normal range.

The person is still independent in his/her daily life in MCI, except for difficulties that the person can usually overcome, such as going shopping with a list despite memory problems. In his/her neuropsychological examination, s/he performs significantly poorly, mostly in memory. Cognitive impairment expressed by the patient or their relatives or observed by the clinician. The presence of cognitive impairment expressed by the patient or his/her relatives or observed by the clinician, impairment in one or more cognitive areas should be objectively demonstrated, and activities of daily living should not be affected. Other factors that may cause cognitive impairment should be excluded. While the rate of conversion of MCI to dementia is 8-14% per year in large series followed longitudinally, it is 50% in 5-year follow-ups. However, the incidence of dementia in the normal population is 1-2% (Gürvit & Yıldırım, 2020).

2.3 What is Dementia, is most common forms and different stages and progression

Alzheimer's disease is the most common cause of dementia, accounting for 60 to 80 percent of cases. Memory complaints, speech difficulties, problems with orientation are prominent. Short-term memory impairments such as forgetting names of people and objects, losing or misplacing items such as keys or glasses, forgetting appointments or anniversaries can be experienced. Language deficits, visuospatial changes including inability to recognize faces or find objects that are in plain sight, executive dysfunction includes inability to use a tool, increasing clumsiness, social cognitive impairment includes not understanding people's feelings as well as sharing in those feelings, losing of interest, motivation can be seen in Alzheimer's disease. A person gets older, their risk of developing dementia increases a lot. In AD, brain atrophy refers to a loss of brain cells or a loss in the number of connections between brain cells, senile plaque associated with aging and neurofibrillary tangle formation are seen. The meta-analysis of prevalence studies done so far in the world shows that AD, which

is 4-5% between the ages of 65-70, increases exponentially every 5 years and reaches up to 50% in the 90s. According to 2019 data, there are 50 million people diagnosed with dementia worldwide. It is predicted that this number will reach 82 million people in 2030 and 152 million people in 2050. One of the most common causes of death for people with dementia is infection especially like pneumonia and sepsis.

Early-onset Alzheimer disease (AD) is defined as having an age of onset younger than 65 years. The development of the disease, out-of-memory clinical presentations, family history are considered atypical. This type is called EOAD ("early-onset Alzheimer's disease"). It is mainly influenced by genetic factors. The typical late-onset presentation is called LOAD ("late-onset Alzheimer's disease") (Gürvit & Yıldırım, 2020).

Dementia with Lewy bodies (DLB) is a neurodegenerative disease that usually occurs between the ages of 60 and 90, producing progressive cognitive decline that interferes with normal life and daily activities. About one-fifth of cases coexist with features of Parkinson's disease. It has an insidious onset, chronic and progressive course like Alzheimer's disease, and it causes memory disorders as well as visual hallucinations, shuffling walk, slow movement, or frozen stance, balance problems and repeated falls, difficulty swallowing, reduced facial expression, sleep disorders difficulty maintaining sleep, early morning sleeping, inability to return to sleep, excessive daytime sleepiness. Autonomic disorders such as urinary incontinence, constipation, orthostatic hypotension may also be observed in the early stages of the disease.

LBD causes changes in thinking abilities. These changes may include: Visual hallucinations, or seeing things that are not present. Shuffling walk, slow movement, or frozen stance, balance problems and repeated falls, difficulty swallowing, Reduced facial expression, sleep disorders, sleep behavior disorder, excessive daytime sleepiness (Gürvit & Demirtaş-Tatlıdede, 2020).

It is generally believed that it affects men and women equally. Patients exhibit behavioral disinhibition or impulsivity even in the early stage of the disease. Some people with behavioural-variant FTD act inappropriately or impulsively, saying or doing inappropriate things without considering how others perceive the behavior. The most common signs of frontotemporal dementia involve extreme changes in behavior and personality. These include making insensitive or rude comments about someone's appearance, making sexual gestures in public, staring at strangers, or being verbally or physically aggressive, missing social cues (while interlocutors find a reason to end the conversation, the patient insistently decide to stay and continue the conversations); burping, farting, spitting, self-touching ; problems in personal hygiene and dressing (smelly, dirty, torn, or inappropriate clothing) ; violation of interpersonal distance. Inappropriate or impulsive changes in behavior include gambling, taking things that don't belong to that person, stealing food or visually stimulating objects, buying or selling of a property without thinking. A person with dementia can experience may experience loss of empathy and other interpersonal skills, such as having sensitivity to another's feelings. The patient may put other people in embarrassing social situations in public where inappropriate comments have been made. Lack of interest and loss of empathy and being insensitive to another's feelings include offensive comments, indifference to the pain and suffering of others, inappropriate jokes, lack empathy. Patients with FTD often have perseverative, stereotyped, or compulsive-ritualistic behavior Repetitive movements like rocking/tapping/scratching/rubbing, complex compulsive or ritualistic behaviors like hoarding, cleaning rituals, obsessive-compulsive checking, constantly going to the bathroom, sequencing objects can be experienced. Patients with FTD may repeat the same words or phrases over and over again. Some changes in eating patterns and unusual food preferences like craving sweet, fatty foods or carbohydrates and forgetting their table manners, overeating and weight gain can be seen. They may also no longer know when to stop eating, drinking alcohol or smoking (Gürvit & Samancı, 2020).

Vascular dementia is the second most common cause of dementia after AD. The term is used to describe cognitive change associated with any cerebrovascular disease. The onset of vascular dementia is usually sudden and focal neurological signs are observed. Magnetic resonance imaging (MRI) is the standard for diagnosis. Risk factors include male gender and a history of stroke. Cognitive impairment commonly occurs in the acute phase post-stroke or in 6 months. Vascular dementia symptoms vary, depending on the part of your brain where blood flow is impaired. The purpose of primary prevention is to prevent vascular lesions (Gürvit & Samancı, 2020).

Stages and Progression of Dementia

Mild stage of dementia: A person living with dementia may have decreased capabilities and functionality. Difficulties with short-term memory, especially recalling more recent events, asking questions repetitively, difficulty finding the right words attract family members' attention. They may become confused in unfamiliar environments. The patient can no longer safely drive, signalling incorrectly, failing to observe traffic signs, making slow or poor decisions in traffic, failing to observe traffic signs. They may have difficulty with numbers and/or handling money in shops. They may fail to learn and use bank cards and mobile phones. They find it hard to carry out familiar daily tasks. There is no problem in dressing, washing, eating manners and basic hygiene yet. There is no behavioral changes except irritability, blunted affect, decreases in spontaneity and a tendency to deny. Sleep disturbance may occur. There are changes in appetite and sexuality. Depression symptoms may be at the forefront in some cases due to recognizing the deficiencies. However, depression often shows itself with motivational symptoms such as reluctance rather than affective symptoms like expression of grief. Visual-spatial disorders, impairments in long-term memory, difficulties in naming, impairments in attention and abstraction-planning can be detected in the examination with a predominance of recent memory.

Moderate stage of dementia

The patient has completely lost his/her independence outside the home. It's common for a person living with dementia to wander or become lost or confused about their location. For a person with dementia, finding the bedroom when faced with a number of doors can be confusing. Dementia patients hardly learn new information. It also affects the ability to read, write and comprehend information. They may forget to change their clothes, put them on in the wrong order or put on many layers of clothes. They may put on many layers of clothing regardless of the weather. People with dementia use spoon, fork or knife incorrectly. A person with dementia pours a glass of juice into a bowl of soup, or eating dessert with a knife indicating that a person with dementia is having difficulty at the dinner table. When he cannot use the knife at the table, his food must be cut beforehand. However, it can be helpful in clearing the table or chopping vegetables. Carers manage bathing, shaving, dental, hair and nail care. In the earlier stages, the person with dementia may only need a reminder to bathe. As dementia progresses, he or she will require more assistance. In washing, they need for help which starts with regulating the heat and cold. Sphincter control is still uneventful except for occasional nocturnal incontinence. The person follows lifelong bathing habits, such as washing face in the morning, going to toilet. A person with Alzheimer's may become suspicious of those around them, even accusing others of theft, infidelity or other improper behavior. Individuals with dementia often have anxiety which can make them feel nervous, worried, or cause them to not want to be left alone or out of sight of their caregivers. Upcoming appointments, such as doctor's visits, can lead to overt anticipatory anxiety. Sleep pattern changes may occur. Mild stage findings were slightly more severe on examination.

Severe stage of dementia

People with severe Alzheimer's are completely dependent on others for their care. He may confuse his relative (wife, child) with his parents, and may not recognize his own face in the mirror. Basic ADLs such as dressing, washing and eating now require full supervision. Difficulty in swallowing also occurs at the end of the disease. One of the symptoms of dementia is disorientation to time, place or person. Someone with dementia may call out for their mother or father. Their vocabulary may considerably get narrow. All verbal abilities can be lost at the end of the stage. Aimless wandering, hoarding, aimless repetitive movements can be observed. They may be unable to walk or stand. Bowel and bladder incontinence may occur. Epileptic seizures may occur (Gürvit & Yıldırım, 2020).

2.4 How is made the diagnosis? What are the benefits, the difficulties and how is it done?

Dementia is an umbrella term for a range of progressive conditions that affect the brain. There are several different forms of dementia and each has its own characteristics. It is important to know different types of dementia and its characteristics so as to know what caregivers are likely to face and what to expect from the patient living with dementia. While primary dementias are neurodegenerative diseases of the central nervous system such as Alzheimer's disease, Diffuse Lewy body disease, and fronto-temporal dementia, secondary dementias occur during the neurological or psychiatric disease and vascular dementia is one of them. Core clinical criteria for all dementia types; decreased capabilities and functionality in everyday activities, significant decline from a previous level of performance and functionality do not occur exclusively in the context of a delirium or another mental disorder. Cognitive impairment should be shown (Gürvit, 2020) gathering information about a patient's past and present medical condition both from the patient and his/her family and (McKhann et al., 1984) mental status examination can be performed at the bedside (for hospitalized patients) or a neuropsychological evaluation assessment of cognitive impairment. Cognitive impairment or behavioral disturbances are manifested by at least two of the following:

- Difficulty in acquiring new knowledge or memory impairment,
- Decreased capabilities and functionality in complex work, impaired judgement or detrimental effects on judgment,
- Visual spatial impairment,
- Language impairment,
- Behavior and personality changes.

Doctors diagnose the cause of dementia by asking questions about the person's medical history and doing a physical exam, a mental status exam, and lab and imaging tests. During a medical history and physical exam, the doctor will ask the person and a close relative or partner about recent illnesses or other life events that could cause memory loss. Non-dementia, acute medical condition and organic pathologies can be detected. A neurological examination is used to detect presence of intracranial event that may cause dementia. After psychiatric evaluation, neurocognitive tests are used to test the patient's level of mental, motor and perceptual functions. This method is used to examine the cognitive consequences of brain damage. During a physical exam, the doctor will look for signs of other medical problems and have lab tests done to find any condition that can be treated. Brain imaging tests such as CT scans and MRI may also be done to make sure another problem isn't causing the symptoms (McKhann et al., 1984).

3 Unit 2: Dementia Change's

In addition to cognitive deterioration, a person living with dementia can experience behavioral changes and neuropsychiatric disorders. Dementia also affects functional ability of the patient. The way dementia may affect personality and behaviour can be very different between individuals. It is important to focus on the things the patient can still do and adhering to lifelong routines.

3.1 Main cognitive changes

Alzheimer's disease typically affects short-term memory area. The patient or a close relative may complain about challenges, concerns on repeating questions, phrases or stories in the same conversation, losing items as a result of their memory loss, forgetting appointments, forgetting to switch the oven, gas hobs, ovens off. The person living with dementia may have difficulty with visual and spatial abilities, disorientation. Getting lost when driving or walking in familiar areas, losing their ability to recognize familiar places and getting lost. Patients with dementia demonstrate word-finding problems (anomia). Primary progressive aphasia may cause difficulty in understanding speech. Their vocabulary begins to narrow. Logopenic progressive aphasia and Progressive non-fluent aphasia may cause difficulty finding the right words and poor grammar respectively.

In Semantic Dementia, the language disorder is characterized by fluent but empty spontaneous speech with loss of word meaning. It should be considered the fact that person with Primary progressive aphasia may experience word-finding problems may be expressed as 'forgetfulness' by a close relative. Agnosia (in greek gnosis- "not knowing") refers to a neurological condition in which a patient is unable to recognize and identify objects, persons. The patient tends to lose mental flexibility, adaptability, focus, and tenacity because of executive cognitive function disorder. The person may have difficulty in grasping the abstract meanings of metaphors, planning his/her behavior, reasoning about individual and social problems, and creating appropriate solutions to the problems s/he encounters in daily life. Social-cognitive deficits considerably overlap in behavioral changes (Gürvit, 2020).

3.2 Main behavioural and emotional changes

Dementia can cause changes in the behaviour of loved ones. A person with dementia who has apathy will be less motivated to do things. Impulse control disorders (hypersexuality, hyperphagia) can be seen. The patient shows less spontaneous (self-generated) emotions regarding their own affairs, or appears less interested in events that should matter to him/her or to people that he/she knows well. Disinhibited behaviours may include: Tactless or rude remarks. A person with dementia may comment tactlessly about another person's appearance for instance. They appear to have lost their social manners, and it can look as if they are trying to deliberately embarrass or harass the other person. Disinhibited behaviours can place enormous strain on families and carers. Inappropriate sexual behavior (ISB, also known as sexually disinhibited behavior, or hypersexuality) can be seen in most dementia syndromes. Sex talk, sexual acts, and implied sexual acts are examples of uncontrolled sexual behaviours.

Hyperphagia is a common eating behavioral change in patients with dementia. It includes unusual food preferences like craving sweet, fatty foods or carbohydrates and tendency to eat non-edible objects such as poop and teabags. Psychotic features of dementia include thought disorders and they may lead to change the person's perception. Thought disorders examples are particularly those of theft ("the caregiver steals my money"), infidelity ("my wife is cheating on me"), and abandonment ("you're going to throw me out of home"),

misidentification “this isn't my house, let's go home” and the Capgras delusion in which someone believes that their loved ones or others they know have been replaced with doubles.

Dementia affects perception. Dementia can interrupt or slow this process down, which changes how a person understands the world around them. These range from very mild perceptual disturbances such as illusions, non-formal hallucinations such as a sense of the presence of a presence in space or vivid dreams to more severe cases with formed hallucinations such as objects, people and animals. As perception disorders become more severe, insight is lost and while they are limited to the night, they gradually begin to appear during the day. Among mood disorders, depression is very common among people with Alzheimer's. Affective-motivational aspects should be questioned. MCI and/or early AD, especially awareness of disability, may be accompanied by depressive states and anxiety, ranging from reactive dysphoria/dysthymia to major depression.

A person with Alzheimer's may feel anxious. He or she may become restless, causing a need to move around or pace. A person is overwhelmed by upcoming appointments. Individuals with dementia often have anxiety which can make them feel nervous, worried, causing them to not want to be left alone or out of sight of their caregivers. Agitation includes physical or verbal violence and repetitive movements. As observable behavioral disorders become more severe, they tend to gradually spread to the day, from being limited to the night, which is called the "sunset phenomenon" at the beginning (Gürvit, 2020).

3.3 Major changes in functionality (daily life activities)

A person with dementia usually requires help with more complex tasks, such as managing bills and finances. People with dementia can continue with day-to-day finances, such as paying for shopping, but may have difficulty with more complex decisions. For example, the person may find it difficult to learn a new washing machine/dishwasher, TV remote control. A person living with dementia find it hard to maintain a household and self-care or hygiene (dressing, washing, eating, toilet, etc.). Considering that especially patients in the early period may have a tendency to deny, the relatives of the patients should be carefully questioned in this respect if possible (if necessary).

Compared to Alzheimer's disease in terms of behaviour

FTD often begins with distinct behavioral changes (socially inappropriate, apathetic, impulsive, etc.) while people with Alzheimer's disease in the early stages tend to remain socially skillful despite their memory problems (they may even become adept at covering up their difficulties). People with AD usually have an early and profound difficulty learning and retaining new information. In contrast, most mildly impaired FTD patients generally know the day or time and their location, and they are able to keep track of recent events and can continue to stay independent, including living at home, working, driving and more (Gürvit, 2020).

4 Unit 3: “In My Shoes - Person Centred Approach”

Before starting to read this chapter, take some time to listen to the podcast and try out the proposed exercise.

4.1 What is it like to have Dementia?

Anyone who has come across a Person with Dementia cannot help but ask themselves this question.

Tom Kitwood (1997) asked this same question when he began to study identity in People with Dementia. There were those who said that the diagnosis of dementia could be considered a synonym of many losses, including the loss of the person's own identity. However, Kitwood addressed this difficult topic, presenting several ways of dealing with this situation. On the one hand, we can try to ask the Person with Dementia directly, although there are rare situations in which the Person himself manages to share his perception of his experience, mainly due to the presence of alterations, such as anosognosia (inability to recognize his own alterations), or even by the stigma that exists on this topic and that does not facilitate sharing. However, there are still some examples that will guide us throughout this chapter, such as Christine Bryden, Jennifer Bute or Diana McGowin, who speak in the first person about their experience of having dementia.

Another way Kitwood used is to listen carefully to the stories shared about their past and how these can be a metaphor for their current situation, such as when the Person with Dementia shares their achievements related to their work as a possible analogy with current difficulties or how the sharing of stories where the focus is on family connection or friendship, convey the appreciation of that same connection and its need in the present moment. Another way could be through artistic creation, where through poetry or drawing, it is intended to understand a little more of the experience, even if it is indirectly, as the author himself tried to do.

Kitwood's final proposal would be through role-playing, putting on one's own shoes. As we invited you to do at the beginning of this chapter. We know that the experience can only be “vaguely” similar, as the real experience can only be inferred, however, through this empathic projection, we can understand what the Person may be going through, not feeling their emotions but feeling the resonances of those same emotions in us.

Several associations and organizations have tried to recreate the experience of experiencing dementia in the first person, either through videos recorded in the first person or through augmented reality games. In all of them, we are invited to observe and “put on” the shoes of the Person with Dementia.

Some examples are as follows;

<https://www.awalkthroughdementia.org/>

<https://www.youtube.com/watch?v=vGrdgm3aPJQ>

<https://www.youtube.com/watch?v=8QSQ0hIToOA>

However, the reader may be wondering why it is necessary to “put on those shoes”? Why would understanding the Person better, in addition to the disease itself, help to take better care of my family member or friend?

We know that one of the greatest difficulties that a Person with Dementia can experience is the fact that, in the face of the diagnosis, their individuality is no longer taken into account, and they start to dominate the changes associated with the disease. As Christine Bryden (2005) shares, “I am carefully watched for signs of strange words or behavior, my opinion is no longer heard, and I am seen as lacking the ability to 'insight', which makes it okay for me to be excluded.” Thus, the person takes a back seat, their interests and values are no longer taken into

account and their opinion is lost in the midst of the changes associated with the disease. We end up contributing to a wider loss than that caused by the disease itself.

It is interesting that, even at an early stage, the Person himself may try to share his difficulties, but these are not valued. As Jennifer Bute (2019) shares: “The family doctor believed in me, but since I was a well-known doctor, they didn't even want to think about dementia. He said, "There's nothing wrong with you." The second doctor I saw was reluctant to diagnose me with dementia as he didn't want to lose me as a local doctor.” She herself noticed the first changes of her disease, however, everyone around her devalued or did not even consider dementia, for fear of the changes that this diagnosis would cause in their lives. It took her to fight to see her own diagnosis recognized, fighting the resistance of those around her.

Dementia is a diagnosis that no one wants to receive, but making it difficult to access that diagnosis ends up limiting access to treatments and support that the Person would not otherwise enjoy. This topic can often be controversial. On the one hand, it is a person's right (UNESCO, 2006), to receive all the information about your health and that it be delivered exclusively to you and, if you accept, shared with others. However, we also know that cognitive changes can influence the ability to pass information to family members and influence the decision-making process (not synonymous, however, that the Person is automatically considered incapable for having certain changes or diagnosis). Thus, an impasse is created that often results in a partial sharing or even a complete absence of information sharing for the Person himself, leaving him without an answer to the changes that he may be feeling. Thus, if even to obtain the diagnosis, the Person may experience difficulties in being heard, we can imagine that, when this is confirmed, he/she may have even more difficulties in being involved.

We know, as we have seen in previous chapters, that dementia can bring with it some added difficulties in recognizing the disease itself. Either because of memory difficulties, which inhibit the person from remembering some of their failures and lapses, or because of anosognosia, where the area of the brain that allows us to recognize the changes to which we are subject is altered, or, passing through changes in the language and their ability to express themselves, there are several changes that can make it difficult for the voice of the Person with Dementia to be heard.

As we can hear in the audio, Christine shares what can be an insight into the experience of having dementia, defining it as living in a constant “fog”, which improves with medication, but which still slows down thinking and reasoning. Christine says “...daily tasks are complex. Nothing is automatic anymore. Everything is as if we were learning for the first time. (...) We are told that we have asked a certain question before, but we have no recollection. It's just a snippet of the blank past, which is weird and scary, and yet they're still frustrated with us. If we had a physical loss, they would congratulate us on our efforts. But since they can't see the changes in our brain and how difficult it is to deal with them, then they don't understand our struggles.” (Bryden, 2005).

Christine thus exposes the difficulty she feels in seeing her difficulties recognized – not only those inherent to the disease, but also with regard to interacting with others. There is a look of expectation, of looking for a mistake or the next loss, losing the look of understanding and appreciation of the Person who still resists the disease.

This sharing brings us to the crucial point of this chapter: How can we respond to these challenges?

From the moment the diagnosis is known, several challenges associated with it arise. In addition to the challenges directly related to the disease, such as cognitive and functional changes, it is also necessary to take into account the psychosocial challenges that may arise.

The impact of the perception of the disease on the Person itself is of great importance, because often, even with the presence of significant changes, the Person does not fail to have a perception that something is different. The most common response is to dismiss these complaints, saying things like "it's normal", "it's part of age" or "don't worry!" The point here is not to increase the Person's own anxiety or to force them to be aware of their changes, but to enable dialogue on the subject, allowing the Person to share their natural concerns, without being interrupted or the possibility of dialogue being "cut off" right from the start. We may not have a solution for the situation itself, but the fact that we are at the side of the Person, available to listen, makes it possible for them to have another "port of shelter" in these uncertain times.

Because there will be doubts and questions that arise, not only for the Person, but also for the people around them, it is essential to understand the disease through reliable information and the support of professionals. This sharing of information can be reflected in the communication of the respective diagnosis with the Person with dementia, something that is not yet common nowadays, but which is still a right of the Person himself. Of course, we can understand the reasons for this to happen, from the outset the fear that the Person may not be able to understand or remember the information shared, however, this point must be evaluated on a case-by-case basis, and there will be situations in which, in fact, sharing the diagnosis can be beneficial, so that the Person can better understand and deal with what is happening. Often, there is the adoption of a "conspiracy of silence", where the family and medical team know about the diagnosis, but the person ends up not having the opportunity to know it. At these times, various decisions are also made for the Person, such as the type of care provided or the medication to be taken, without truly involving the Person in the decision-making process. Oppositional behaviors are common:

- "If everything is fine, if I don't have any problems as they tell me, then why do I have to take these medicines?"
- "If they tell me I'm fine, why do they want to take away my driving license?"
- "If the doctor told me I was fine, why is there a stranger here to take care of me?"

Wouldn't we also have the same reaction if we were in the Person with Dementia's place?

4.2 Introduction to the person-centred and human rights-based approach

We know that each Person is unique and that each situation will have to be analyzed based on this principle, however, when we start to adopt an approach in which we "put on the shoes" of the Person with dementia, we are able to begin to understand some of the situations and challenges that will arise along the course of the disease.

Jennifer Bute presents a beautiful analogy in her lectures, where she addresses the issue of Dementia in the first person. The first image of her performances is always poppies. She associates this flower with hope and joy, but above all with resistance over adversity, as they can "Grow along new highways, in those unexplored places where we can feel lost; to come across poppies in a smooth and empty landscape, between the gravel and dust, gives me immense joy"(Brute, 2018). People with Dementia can also thrive in the face of the most inhospitable conditions, if, like the flowers themselves, they have access to the conditions to do so, to an approach that is more focused on their needs.

This approach is often called the “Person-Centered Approach”, where the focus is, as the name suggests, on the Person himself, his life story and his interests and values. (Kitwood, 1997) , a pioneering author in this area, defines 5 great needs of the Person with Dementia, having as a sixth central need, Love. The other domains are Comfort, Identity, Occupation, Inclusion and Connection, often represented as a flower.

As he himself says, the correspondence of one of these needs will provoke the correspondence of others, as there are no solid barriers between each need. These needs are present in all human beings, but they may be even more evident in people who face some type of loss of cognitive capacity, who, because of it, may see their ability to take initiatives to meet these same needs jeopardized. Thus, responding to these needs, we can continue to respect the Person and his/her history.

To show the importance of the person's life story, we present the following example, taken from the “Dementia Friend’s” campaign:

In a nursing home in the North East of England, one of the residents, a Person with Dementia, was constantly drumming on all surfaces. Tap, tap, tap. Tap, tap, tap. This became very annoying for both the staff and the other residents, especially since they couldn't do activities when she was doing it.

One day, her niece came from Australia to visit her. Naturally, the first question she asked was “Why is she doing this?!” . Regrettably, she didn't know.

Home staff spent the rest of the afternoon with the niece, trying to get more information about the resident. One of the things they discovered was that during World War II, she had worked at Bletchley Park and had helped to decipher the Enigma code that helped end the war. She was receiving messages transmitted in Morse code! Instead of "tap, tap, tap" it might have been, "dot, dot, dash."

As we can see, it was only possible to understand the behavior considered “atypical” through the perception and appreciation of the Person's life story. When we understand the importance of a certain gesture for the Person in question, we can see that it is a very typical gesture and a memory of a present past. Often, it is this same knowledge about the Person that allows to unblock more adverse situations, guide in situations of disorientation/confusion or calm down in moments of greater agitation. I may not recognize the context where I am, I may even, momentarily, not recognize those around me, but if someone talks to me, with matters that interest me and that concern my interests, much more easily I will find tranquility and security close to those same people.

When we include the Person's story in everyday life, we are able to create a safer space for the person to “move around”. Through activities designed based on the interests of the Person, in the construction of a valued routine with space for novelty, we are enabling a better quality of life for the Person himself and for those around him. If we have the opportunity to involve the Person himself in this daily planning, on the one hand we value their skills, but we also give them the opportunity to make decisions, no matter how simple they may be, but which contribute to giving the Person back the feeling of usefulness and productivity, which any human being needs in their day-to-day. When we recognize and value the life story of the Person with Dementia, many “strange” behaviors start to make sense, and we thus have the opportunity to meet the need, feeling or habit that is at the base of that situation.

This increased care for the history and interests of the Person is not only a way of improving the provision of care, in a more humane and respectful way, but also a respect for the Person's own identity. It is often questioned whether the Person with Dementia remains the same after the progression of the disease. There are several changes, namely cognitive changes that end up influencing the behavior and autonomy of the person. However, what can define the identity of the Person?

4.3 Identity and Dementia

The literature on this topic is extensive and there are several theories about it. As can be seen in the work of (Caddell & Clare, 2010) , where a review of the various existing studies on this topic was carried out, almost all of them showed some evidence that the identity persists in the Person with Dementia, visible through their words and their non-verbal behaviors. Through the ability to talk about their physical and mental skills, to recognize and be recognized through behaviors and phrases “proper” of the Person, whether through the social interactions they establish, with a search for meaning and purpose for that same interaction , People with Dementia can thus maintain an identity, even if their ability to present their life narrative in a coherent way may be jeopardized by the changes. The interesting thing about this literature review, in addition to reinforcing that the identity of the Person with Dementia is maintained, is that it used studies that interviewed and evaluated People with Dementia at various stages, from the earliest to the most advanced.

On the other hand, studies by Carpeter and his collaborators (Carpenter et al., 2007) and those by Auriemma and his collaborators (Auriemma et al., 2014) showed that values and preferences prove to be consistent over time in People with Dementia and that they are stable enough to be used to keep the decision centered on the person, even when the person loses capacity.

Thus, even in the face of Dementia, the identity, values and tastes of the Person can remain preserved, even with slight changes, which can be a guide for the provision of care. Even though it is always necessary to have space to accept any change of opinion of the Person himself, the literature gives us bases to be able to base the provision of care on the interests and values of the Person himself, thus being able to be a good aid in the decision-making process when the Person finds it difficult to make those same decisions.

In addition to the scientific literature, there is nothing like hearing the answer given by the Person himself. Sharing the words of (McGowin, 1994): “If I am no longer a woman, why do I still feel one? If no longer worth holding, why do I crave it? If no longer sensual, why do I enjoy the soft texture of silk against my skin? If no longer sensitive, why do moving lyric songs strike a responsive chord in me? My every molecule seems to scream out that I do, indeed, exist, and that existence must be valued by someone! Without someone to walk this labyrinth by my side, without the touch of a fellow traveler who understands my need of self-worth, how can I harden the rest of this uncharted journey?”

From her words, we can understand the resilience of identity and that the needs of a Person with dementia are the same as any other human being, the need for contact, validation by the other, the simple response that any of us has when listening a song, for example. One thing that McGowin reinforces is the fact that, in the face of the uncertainty of dementia itself, support, a companion, may be needed on this journey. Christine herself reinforced the idea of a journey, that is, that dementia is not something stagnant, in which the person quickly goes from

“healthy” to “sick”, but rather someone who faces adversity and who can and, inevitably, to lose some skills but who can still be involved in the smallest tasks, in relationships with others, or even in the community itself.

Thus, it is up to each of us, who work or live with People with dementia, the challenge and the mission of continuing to respect their identity and their rights, and never forget that there is more beyond illness, doing this daily effort / exercise: put ourselves in the person’s shoes, and see the world through their eyes.

5 Unit 4: First steps on caring – Family Focus

Introduction

In this chapter you will learn about how the relationship between the person with dementia and the carer may change over time, what emotions the carer and the person with dementia may experience and how your attitude towards dementia can impact your caregiving relationships. How to navigate the changes in relationship among family and friendships from the start of the dementia to later progression, as well as how to receive support. This chapter will also teach you how to discern between dementia specific and non-dementia specific problems. The chapter regards the communication with the person with dementia, about the changes that can occur due to the dementia and how to communicate with the person with dementia. You will learn also about the importance and the power of non-verbal communication. The other important aspect is about different technical teams that can provide help to you as the person with dementia or as the carer of the person with dementia.

Objectives

- Identify different roles of caregivers and how the relationship with the person with dementia may change following the diagnosis,
- Identify potential attitudes, and emotions the person with dementia and carers may experience in the caregiving relationship,
- Learn strategies of coping with dementia and providing adequate care for the person with dementia,
- Understand how the person's ability to communicate can be impaired by dementia,
- Identify the strategies of communication with the person with dementia,
- Know how to use the power of non-verbal communication to your advantage,
- Understand and being able to identify different technical teams involved in the care over the person with dementia,
- Know how to communicate with different teams that take care of the person with dementia.

Reflexion

- What is my relationship with the act of caring?
- What are my attitudes towards dementia? How did my attitudes towards dementia change from caring for the person with dementia?
- How has the relationship with the person with dementia changed?
- How successfully have I leveraged the support groups available to me?
- How do you communicate with the person with dementia?
- In what ways has non-verbal communication shown helpful in communicating with the person with dementia?
- How well have we leveraged on support for people with dementia?

5.1 How do I relate to dementia?

Dementia is often diagnosed following a crisis event or the onset of severe symptoms. However, early diagnosis allows people with dementia, their families and their carers to prepare. Progression of the condition has implications in areas such as personal safety, use of motor vehicles, management of personal finances and access

to assistance. Diagnosis can help family, friends and people with dementia to accept and understand their functional impairments. It allows time to plan future living arrangements, appropriate care and assistance, legal and financial matters and appropriate medical treatment.

Diagnosis of dementia can be a great shock for the person as for those closest to them. Many people with dementia after the diagnosis feel sadness and loss, which are connected to the realisation that they won't be able to enjoy in activities they were planning on enjoying them or they enjoyed them. Denial is often a response to the diagnosis of dementia. The person that has the dementia can experience the great fear over their own future or even feeling guilty that they are at fault for the dementia, that they haven't done enough that they would stop it. Some with the diagnosis may feel a relief as it may explain to them the changes that were happening to them. For relatives it is important that after the diagnosis receive as much information about their illness and their predicted and unpredicted problems stemming from them. The more information that the relatives have the easier it is for them to take care of the quality of life of the person with dementia that for them and that are brave in facing the illness.

5.1.1 Caregiving relationships

The problems of people with dementia and their relatives can occur, as their relatives don't identify the changes due to the illness or may think that the problems occurred due to the different reasons. Some may think that changes are the consequence of aging or are convinced that the person with dementia causes problems on purpose. The people with dementia and their relatives often experience that the roles in the family and in the closest relationships change. This is how the children and partners of the person who is sick often have feeling that they have overtaken the role of the parent, people with dementia feel that their relatives and the people around them treat them as children. Some relatives are reporting that their interrelationships have deepened and that they were able to become closer with the person with dementia.

Different relationships with the caregivers can vary according to the kinship and how they are related to the person with dementia. Caregiving can have a positive and or negative impact on the carer. There are positive aspects of caring for someone that include feelings of affection and closeness within the caregiving relationship and the sense of personal satisfaction and purpose in life. The impact can however also be quite negative on the carer, for example the person providing for a person with chronic illness is ongoing, demanding and stressful, which can have negative implications for the mental health and well-being of carers.

5.1.2 Different roles of caregiving relationships

As the symptoms of dementia worsen over time the person with dementia will need care and support. If the person with dementia has been used to managing their own or the family's financial and social affairs, this can be hard to accept. It can also be difficult for the person who now has to help the person with dementia, as the balance of your relationship with them will change.

Over time a change towards guardianship can occur, which is the role of the of safety of adults that are not able to take care of themselves. Guardians are responsible for taking care of the people in their care, their rights and in favour of their properties. Informal carer is someone who is a member of the family, friend, or neighbour who, in an unpaid way, provides support to a physically, emotionally, financially and informally ill or physically disabled

person (Bove et al., 2016; Horrell et al., 2015; Vaingankar et al., 2013). The guardians are responsible for taking care of themselves, their rights and carefully take care of their financials. Guardian is responsible for taking care of the person in their care. It is obliged to yearly speak with the Center for social work about their work and submit financial report. Guardian can only with the approval of Center for social work take away the real estate, take away the carers real estate with larger sizes, give up on heritage or reject the gift.

Guardianship for special cases is simple and fast procedure, that can be used by the relative with dementia. The procedure to receive such lasts from one to two months, or this type of guardianship is not important that the person receives the agreement with the person with dementia. The person that is not placed under such guardianship, their business ability is not taken away, however they are given the guardian only for the specific task or procedure where the guardian protects their interest. The role and procedures should be unique. Such as the signing of a contract for institutional care, handling the added for help and service. The person with dementia is in such circumstances not placed under guardianship, as this is only there under a case of specific circumstances where the carer is used to protect the application of a role for institutional care, handling the individuals interest. Such case of guardianship is only used in limited way and only to relieve the problematic situation. Guardianship for special cases stops when the role for which the carer has been assigned for stops.

Taking away the peoples operating abilities may come when the person is not able to take care of themselves, their rights or benefits. The decision to take away the person's ability to work is decided upon by the court upon the nomination of the Center for social work. The taking away of the operating abilities can be partial or complete. For the time being at the court the court can bring the proposal by the centre for social work, relative or someone who lives together over longer time in the common household or community. Taking away someone's operating capacity can be partial or complete. For the time being in court the person is given the temporary judge. The person is taken away their ability to work unless it has come to the fact that the hearing may harm the person's health and based on their health the hearing is not possible.

5.1.3 Attitudes and stigma towards the people with dementia

Majority of the participants in a research study by (Hsu, 2020) have shown non-negative (52.7%) attitudes towards dementia, followed by unfriendly (22.5 %), uncomfortable (22.2 %) and finally ashamed (2.6 %). However, the attitudes individuals and carers can have important implications on caregiving relationships and should therefore not be disregarded. A negative attitude towards dementia is related to ageism and the fear of psychiatric syndromes. In cases when negative attitudes become severe this may contribute towards stigma for the people with dementia and this may prevent understanding and compassion towards people living with dementia. Stigma occurs when the perception of others is as deviant from the norm. Even people who report positive relationship with the person with dementia may still feel ashamed, if they have a family member who is suffering from dementia (goto K Aihara Y Kato H. Sugiyama T., 2016). There are three kinds of stigma, such as public stigma; which refers to the general public that carries a negative belief towards dementia, the self-stigma; experienced or internalised negative belief such as perceptions of the people with dementia or their carers about the disease and their own perception and finally the spill-over stigma; which refers to negative experience due to social proximity, such as stigma of caregivers towards people with dementia and caring after them due to experience of the person with the illness (Stites et al., 2018). Stigma and negative attitudes towards caring after people with dementia can negatively impact the caregiving relationships. The research by (Ošlak & Musil, 2017) showed some statistically significant differences in experiencing stigma considering some social-demographic factors. People that had already had some contact with dementia person with dementias in the past showed

lower level of personal avoidance. It was also found out that experiencing negative views and desire for avoidance of dementia person with dementias positively correlates with not seeking help and delaying seeking help in experiencing early signs of dementia.

People with lower socio-economic status, lower education and less health literacy, while also the misunderstanding of the dementia can cause the unfriendly feelings towards the people with dementia. The reason being could be that the less resources may mean also lower ability to care for people with dementia. In such cases knowledge on how and where the carer can get assistance and how to handle problems with caregiving this may produce negative and unfriendly feelings. Understanding how one may feel about dementia may enable them to seek help and support and provide caregiving that is appropriate for the person with dementia. For example, research has shown that better knowledge is more likely to be related to the non-negative attitude towards people with dementia than feelings of shame. For example, people were more likely to be ashamed, if they had lower knowledge about dementia and had a family history of dementia in their family. Understanding and learning about dementia and what it means to be a caregiver may therefore provide an important bridge against negative attitudes and to create positive attitudes towards caregiving. Self-stigma towards dementia can cause reluctance to seek help. However, knowledge without friendliness and positive perception of dementia may not necessarily improve the friendliness towards dementia (Hsu, 2020).

The family represents an important frame for individual's development and caring. Positive family environment is present when the family is interested in the person with dementia. They are ready to accept the new situation and adapt to it. Everyone inside the family learns and tries to gather the information around dementia. Negative family environment is when the individuals in the family are negative towards the person, they try to get rid of the person, put him or her into the home for the elderly and leave the care to others. They do not participate in treatment of the person with dementia. In such cases the treatment outcomes are bad and the family environment is difficult and negative for the person and the outcome of the treatment. Fake positive family environment is present when the individuals care for the person, they sacrifice for him or her and are overly protective of him or her. The work that the person could do on their own they do instead of them. In such environments the person with dementia is placed on the level of a young child. The more the person is unable to care for themselves the more they have to care for him or her and sacrifice for them. Such sacrifice the environment supports. In passive family environments relatives do little for the person they care about. They wait for others to take care of them. It is often how it may occur at the start of the disease progression. Later on when the relatives learn about what they can do on their own, they get activated and a positive environment can happen. It is important that we understand when the families are leaning to the negative environment and that we encourage the positive family relations. It is important that the family is given the appropriate support (Mencej, 2009).

5.1.4 Emotions

People with Dementia

A diagnosis of dementia can have a huge impact on person's life. This can create a range of emotions when diagnosed with dementia. These emotions may include grief, loss, anger, shock, fear, disbelief and even relief in some circumstances. People may struggle to deal with these emotions and may move between emotions in order to adjust. They may feel afraid over their future, scared about moments of confusion and forgetfulness, and upset about the impact that dementia may have on the people around them. Confirmation of diagnosis may in some

circumstances trigger depression and anxiety in some people. It is important that both the people around them feel that they are able to and are encouraged to express their feelings.

Those closest to the person with dementia may also have their own emotional reactions to cope with the diagnosis. It is important and that both the person with dementia and those close to them are able to and are encouraged to express their feelings. In some cases a relief may come from knowing what is wrong, so they may re-evaluate and plan ahead. This experience can be used to re-evaluate the situation and focus on the activities and relationships that make them happy.

People with dementia may experience the loss of confidence and they may feel insecure about themselves and their abilities. In many cases people with dementia may feel that they are no longer in control and often don't trust their own judgement. They may experience stigma and social demotion. Especially, since they may not be treated in the same way by people due to their diagnosis. This can lead to have a negative impact on the individual's self-esteem. Nevertheless, this should not be the outcome we strive towards. Some people may in different circumstances form new relationships such as attending a class or a support group. In such cases high-self-esteem allows for individuals to cope much better with chronic health conditions.

This is why when caring for or interacting with people with dementia we may offer the person plenty of praise and encouragement, celebrate successes and focus on positives, avoid harsh criticism and belittling comments, ensure that they have enough time to do their activities they enjoy and give them person, if a person makes a mistake, be supportive while help them to maintain social relationships and form new ones. It's important to talk about your feelings and frustrations. It's also important to keep in contact with family and friends. And try to make new friendships through local activities and support groups. Join groups in the local environments that are dementia focused. Having dementia does not mean your life is over, even though your abilities and independence may worsen over time. However, it may mean that there is a need for adjustment and preparation and change in caregiving relationships.

Carers of People with Dementia

Dementia can be considered as the step-by-step loss, the loss of skills, remembering one's identity and personality, which is difficult to face. The person with dementia gets lost in their own neighbourhood, forgets the birthday of their son that happened a few days ago, in everyday social situations does not respond correctly, laughs, or makes jokes at sad events. Some of the most difficult moments of coping with illness is when the person does not recognize them anymore, the moment when they must start thinking of sending them to homes for the elderly or the times when they become violent. The relatives often feel the feelings of guilt, sadness, and shame, often also anger, powerlessness and hopelessness.

Stress and exhaustion are common situations among informal carers, and it has been found that emotional exhaustion is closely related to depersonalization, anxiety and depressive symptoms. Therefore, it is important to learn how to recognize signs of stress, in order to avoid reaching high levels of exhaustion. It can result from the informal carer's tendency not to ask for help, or to try to do more than they are capable of, as they feel they are overwhelmed by their caregiving experience and lack physical, mental, emotional, or financial support(Pathak et al., 2020). It is, therefore, a consequence of a persistent lack of self-care , due to the great amount of attention given to the person in need. They may also experience difficulties in separating their role as carer from the one of spouse, child, or friend. The distinguishment is important, as it is important that certain issues arise from family and personal relationships and some are dementia specific.

Sometimes negative emotions may arise as carers get their hopes up and believe that their care will have positive effects on the health and happiness of the person they are caring for. However, this may be unrealistic, for example for person with dementias who have a progressive disease such as Parkinson's or Alzheimer's. Carers might get frustrated due to the lack of money, resources, and skills to manage their loved one's care well, which all leads to negative attitudes towards the person with dementia (Hsu, 2020) or they might take on too much, partly because they see providing care as their only job (Pathak et al., 2020). All of which, can lead towards negative attitudes towards the people with dementia.

5.1.5 Dementia specific problems in caregiving

People with dementia, may have impairments in language, memory, perception, personality and cognitive skills. This can have a negative impact on everyday functioning. This can cause problems in familiar tasks, such as shopping, reduced capacity for decision making, in problem solving and providing judgements, confusion and disorientation in relation to people and places. The problems in communication can occur through the loss of speech and ability to understand language. With dementia progression the basic and core activities will become impacted, such as self-care (example bathing and dressing).

On the other hand, people with dementia may also experience behavioural and psychological symptoms of dementia. This represent the non-cognitive symptoms that include psychosis, aggression, agitation, depression, disinhibition, delusions, wandering, repetitive questioning and incontinence. These symptoms are often associated with lowered functional abilities, poorer prognosis, increased burden on caregivers, higher costs of care and earlier hospitalisation. The presence of deliriums and hallucinations may especially mark the different service required in comparison to people who do not experience these symptoms. Dementia is not a static condition; this means that changes happen at both the personal and service levels. These transitions can however have a profound impact on the quality of life of the person with dementia, their families, and carers (Gilham, 2009).

The background information, observing and listening to the person with dementia, can gradually build the personal care routines and preferences of each individual and in such a way, we may ensure that what is the personal self-identity is preserved while we care for the person in need. Refusing help is how some people communicate their need to believe that they are still independent. It is very important that we respect this and ensure that we help people to do everything that they can still do for themselves. It is often easier for a person to accept help with aspects of a task that they find difficult if they have a sense of achievement gained through completing some parts of the task on their own.

5.2 Communication with the Person with Dementia

Every conversation has the start, flow and an ending, however for the people with dementia every part of the conversation is challenging. The communicator sends the message to the receiver, this interprets the message and responds whether the received the message. It is important to understand, which method of communication is the most effective and design the environment for positive and effective relationships and communication. When communication is not effective double helplessness can arise. The person that is cared for is helpless because he just doesn't know what to do and we're helpless for a short time because they just don't know how to react.

Starting conversations and keeping to the topic can be impaired as the person may experience difficulty forming ideas and concentrating. The ability to speak clearly may be impacted by speech that may sound 'confused'. The progressive nature of dementia means that over time the person may experience:

- Their fluency when talking may deteriorate,
- They may interrupt, not respond, ignore others, appear self-centered,
- jumbled speech,
- use of the 'wrong' word, e.g. saying 'kitchen' when you mean 'bathroom',
- struggling to find the right word,
- hesitations and repetition,.
- going off on a tangent/losing focus on the topic,
- speech slurred/sounding less clear,
- joining in with what is going on or following what others are saying,
- being able to answer questions appropriately,
- thinking of names of people, places or objects,
- being able to think of anything to say,
- The way they express their emotions will change,
- Their ability to write may become impaired,
- They may have hearing and visual problems as well.

5.2.1 How to communicate if you have dementia:

Tell those close to you what you find hard and how they can help you. For example, you may find it helpful if people calmly remind you:

- what you were talking about,
- what someone's name is.

Some other things that may help the person with dementia to have an easier time communicating with:

- making eye contact with the person you're speaking with,
- turning off distractions like radio or TV,
- asking people to talk more slowly and repeat what they have said if you don't understand it,
- asking people not to remind you that you repeat things.

As dementia progresses it will become harder to communicate. Therefore, it is important to find other ways to build a relationship and communicate with the person with dementia. This can be done by changing your verbal communication to non-verbal communication, e.g. being calm with the person, putting the person at ease wherever possible, and thinking about the environment in which you see the person (can it be familiar, somewhere where they feel safe). Give the person time and do not make them feel rushed. Ensure that you are visible and that they can see you clearly and hear you clearly. Spend time with the person or work with the carer to understand the person's facial expressions and body language.

- Say the person's name to gain attention at the start of the conversation and throughout,
- Try to sit at the same level as the person with a dementia,

- Touch,
- Choose a safe and appropriate place to have a conversation,
- When more than one person is present try to have only one person speak at a time,
- Make eye contact,
- Take your time, repeat the message and wait for response. Repeat yourself if you are unsure the person, with a dementia has heard or understood you,
- Gently remind the person of what they or you were saying, e.g. “you were just telling me”,
- Be understanding of the feelings of the person with dementia,
- Introduce the topic and ‘set the scene’ for the person, e.g. “I’d like to talk about your brother John”,
- Speak slowly, clearly and distinctively,
- Don’t correct the person while speaking, don’t oppose and don’t argue,
- Use short, simple sentences and use one theme per conversation,
- Don’t correct the person while speaking, don’t oppose and don’t argue.

Even, if the communication with the person with dementia doesn’t go smoothly. Do not stress the person with dementia to respond; Encourage an individual to use any way of communication he or she feels comfortable with, for example, gesture or writing; Use touch to help concentrate, to set up another way of communication and offer security and encouragement; Avoid confrontation and conflicts with people with dementia (Zlobec et al., 2017).

5.2.2 Non-verbal communication

People become very sensible to the nonverbal communication. Often times people with dementia can act as a mirror. For example, if they will see another person happy they will also become happy, however if they sense negative emotions the mirroring will happen and they will pick up on your negative emotions. It may also happen that failure to communicate with the person with dementia may lead to aggression. Sudden movements, the tone of your voice or a tense facial expression can upset or distress them, even if the words you say are not upsetting. This is why as we communicate with the person with dementia, we must become very sensitive to the non-verbal communication we show or how we may act with the person with dementia(Zlobec et al., 2017). Non-verbal communication may be especially important if they have reverted to the first language they learned, and you do not understand or speak this language. If a person is finding any kind of conversation too difficult, there may be other ways that they can communicate their emotions. Art therapies and activities such as drawing, painting, music, poetry and drama can help a person with dementia to express themselves. During the later stages of dementia, the person may not be able to communicate much at all. It may still be helpful to talk to the person, and communicate by touch if it feels appropriate, for example by holding their hand. Even if they don’t respond very much, or at all, they may feel a level of connection with you and a sense of comfort.

5.3 Communication with the technical team

Having dementia or being a carer of the person with dementia will need you to interact with various people to handle guardianship, take care of the person with dementia or receive help and support in providing care for the person with dementia.

5.3.1 Who represent the care team?

A care team is the group of people who you'll partner with and rely on to provide you help, care, support and connection throughout the course of the disease. The person with dementia is in the center, but you are not there alone. The help provided by others can minimize stress and feelings of being overwhelmed. Developing your own network of helpers may help you lead a more productive, active and engaged life while living in the early stage of the disease. Getting people to help you with certain tasks works better with a well-thought-out plan rather than trying to find help in an emergency situation. This plan will provide you — and the people assisting you — with confidence that the assistance you need will be there when you need it.

Family, friends, neighbours, professionals and your community are all part of your care team. Start building your team by identifying a decision-maker you trust. Often this person is a family member or friend. Have a conversation with this person about the type of help you may need and your long-term priorities. Build up your team with other helpers.

5.3.2 Collaborative care

A primary care physician's (PCP) practice is generally the place to start when questions about cognitive impairment arise, because these symptoms may be connected to other issues in a person's total health picture. Primary care doctors and nurses are likely to know which initial questions to ask and which screening tests to do. Depending on the symptoms, they may do a physical examination, draw blood, order imaging studies, and suggest consultation. Consultation with one of the following specialized professionals, often at the recommendation of a primary care clinician, can be valuable. This is especially true when dealing with a more complicated situation such as a person whose age is young, whose cognitive symptoms are unusual or confusing, whose medical or psychiatric histories are complex, or whose behavioural problems are making it difficult to care for them.

The centrepiece of a successful collaborative care model is the initial evaluation providing expert clinical evaluation and diagnosis of the person with dementia, assessment of caregiver and person with dementia needs, provision of supportive counselling, referrals for community resources and development of care plan with short-term, intermediate and long-term goals. These components are completed by different team members, who bring unique expertise and perspective to be integrated in the collaborative care model.

Specialists and Their Roles:

Role of the Physician

- Diagnosis of memory disorder and initiation of care plan,
- Review of brain imaging and laboratory tests, if indicated,
- Evaluation of person with dementias with unexpected change in condition, atypical or unusual presentations,
- Available for person with dementia emergencies,
- Referral to Medicare Part A services (home care, hospice) depending on state regulations,
- Role of the nurse practitioner or physician assistant,
- Re-evaluate plan of care and provide ongoing assessment of cognition and associated symptoms,

- Coordination of care with other disciplines and medical providers,
- In some collaborative models, the NP may be the clinician making the initial diagnosis, completing the initial assessment and identifying a plan of care,
- Referral for outperson with dementia services (i.e., physical therapy/occupational therapy),
- Follow-up of all imaging and testing results,
- Person with dementia and family education on pharmacologic and nonpharmacologic interventions,
- Medical doctor and nurse practitioner collaboration.

In our collaborative model, the MD leads the initial evaluation, makes the diagnosis and initiates the medical work-up, and the NP focuses on evaluating the person with dementia and caregiver in follow-up for medication and symptom management, and reassessment of behaviour, mood and function (Litaker et al., 2003). With the NP able to see follow-up person with dementias, the physician is free to see more new person with dementias, increasing clinic capacity and shortening wait times for new person with dementia appointments. Other models can also be employed again depending on the practice with the end goal of utilizing each provider's strengths and skill set. The NP can serve as the bridge to outperson with dementia and community referrals by melding the medical and nursing models of care.

Role of the registered nurse

- In some collaborative models, the RN may serve as the care coordinator and manager (ANA, 2012; Lamb et al., 2010), particularly if there is not an NP or physician assistant as part of the team. Generally, an RN serving this role will have at least a bachelor-level degree,
- Performs routine vital signs on person with dementias in the office,
- Perform memory and functional screening or monitoring tools that allow for objective re-evaluation of change in performance and/or function over time,
- Person with dementia and caregiver phone follow-up, clear up confusion about instructions and follow-ups and prevent or correct any medication errors,
- Assists with outperson with dementia referrals to disease specific organizations and similar useful person with dementia and caregiver resources,
- Role of the social worker,
- Educates about memory loss and caregiver issues,
- Offers referral for concrete services (transportation services, assistance in the home, meal delivery and adult day programs, guardianships),
- Provides assistance with transition to alternate care settings,
- Provide psychotherapy and consulting services (billable service),
- Refer to or lead support programs for person with dementias and/or caregivers,
- Collaborates with local agencies and organizations,
- Provides educational resources and materials.

Role of the medical assistant

- Coordinate paperwork for office visits to complete in the waiting area,
- Assist with completion of documentation (long-term care insurance, adult day program paperwork, referrals),
- Coordination with collateral source – caregiver, family and friend,

- Provide feedback on person with dementia's ability to manage appointments and compliance,
- May complete simple screenings (cognition, fall risk assessment).

Role of a neuropsychologist

- Trained to perform and interpret neuro-psychological testing,
- May play key role in diagnosis and monitoring of person with dementias,
- In role of a psychologist, may provide consulting and therapeutic services,
- May lead cognitive remediation or retraining programs,
- Role of a health educator,
- Generally, at least a bachelor-level, more commonly master – prepared individual with training in psychology, social work, sociology, medicine, public health or neuroscience,
- Trained to perform neuropsychological testing, however interpretation of tests is performed by MD or psychologist,
- Complete surveys with person with dementia and families,
- Maintains print and electronic library of resources and health information,
- Coordinate distribution of health information materials consistent with MD, NP and recommendations.

6 Unit 5: Care Strategies

Introduction

People with dementia may need help with different daily activities. In this chapter you will learn what daily activities are appropriate for the person with dementia and how the caregivers can prepare to structure the daily activities from morning to evening. You will also learn about what changes you can expect with the person with dementia and how it may implicate their safety, you will also learn how to establish and maintain safety of the person with dementia.

Objectives

- Being able to identify the appropriate daily activities,
- Learn to structure the daily activities and day of the person around daily activities,
- To identify the potential safety implications for the person with dementia s disease progresses,
- Establishing and maintaining a safe environment.

Reflexion:

- How have I been structuring the daily activities for the person with dementia?
- What daily activities can the person with dementia still perform?
- How does the establishment of the structure impact the person with dementia?
- What types of changes in behaviour that has provided safety concerns have you noticed from the person with dementia?
- How safe is your environment for the person with dementia and how to adapt it?

6.1 Strategies for Major Cognitive and Behavioural Changes

Dementia can cause changes in the behaviour of friends and loved ones. Such changes are very common, but they can place enormous stress on families and carers. Understanding why someone is behaving in a particular way may help families and carers to cope. There are many reasons why a person's behaviour may change. Dementia is a result of physical changes in the brain, and these can affect the person's memory, mood and behaviour. Sometimes, behaviour may be related to these changes, but at other times, the behaviour may be triggered by changes in the person's environment, health or medication.

Understanding the cause will help you to decide which strategies may be helpful. Some carers find that keeping a log or diary helps them to see a pattern of behaviour that may be developing, and this helps them to identify the cause of the changes. Always discuss concerns about behaviour changes with your family doctor, who will be able to check for the presence of a physical illness or discomfort. The doctor will also be able to advise if there is an underlying psychiatric illness (Better Health Channel, 2014; Victoria Department of Health, 2015).

Table 2: Cognitive and Behavioural Changes

Behavioural symptoms	Nonpharmacological Strategies
<p>Wandering</p>	<ul style="list-style-type: none"> • keep objects that might encourage wandering out of sight (for example a coat or handbag), • make sure the person with dementia’s room is convenient for observation, is away from stairs or elevators, and is located so the person with dementia has to pass the nursing station to reach an exit, • make sure all staff are alerted to the possibility of the person with dementia wandering, • provide appropriate opportunities for exercise and activity. The family or carer, allied health assistants or trained volunteers can help (for example, take the person with dementia for a walk within the hospital grounds at appropriate times), • designate a safe place for the person with dementia to mobilise, • ensure the person with dementia has identification intact at all times. Keep a description of what the person with dementia is wearing on a daily basis and ensure a current photo is available, • check the person with dementia regularly, • consider using a bed or chair alarm.
<p>Sundowning is restlessness, increasing confusion or changed behaviours in a person with dementia with dementia that can occur late in the afternoon or early evening.</p>	<ul style="list-style-type: none"> • use early evening routines that are familiar for the person with dementia; ask their family or carer, • find out what activities or strategies calm the person with dementia (for example, warm milk, back rubs, calming music). The This is me, Information about ‘me’ for planning care in hospital, Top 5 or equivalent form completed by or with a family or carer can provide this information, • allow the person with dementia to mobilise in a safe environment, • encourage an afternoon rest, if fatigue is making sundowning worse, • consider environmental factors, such as lighting and noise, • avoid activities in the late afternoon that may be unsettling (for example, showers, dressings).
<p>Anxiety or agitation may occur which is why it is important to understand the reality the person with dementia is experiencing and validating this may help settle the person with dementia.</p>	<ul style="list-style-type: none"> • talk about the anxiety-producing thoughts, • reassure the person with dementia, • identify and relieve the cause of the anxiety.

<p>Hallucinations or false ideas can be present in later stages of dementia. The person may hear voices or sounds or see people or objects. This can cause severe reactions such as fear, distress, anxiety and agitation.</p>	<ul style="list-style-type: none"> • don't argue and don't take any accusations personally, • maintain a familiar environment, with consistent staff and routine, as much as possible, • ignore some hallucinations or false ideas if they are harmless and aren't causing agitation, • avoid triggers, • pharmacological treatment may be part of a coordinated response for some person with dementias who may benefit from treatment with antipsychotics.
<p>Physical or verbal aggression can be triggered by issues such as fatigue, an over-stimulating environment, asking the person with dementia too many questions at one time, asking the person with dementia to perform tasks beyond their abilities, too many strangers in a noisy, crowded atmosphere, failure at simple tasks or confrontation with hospital staff.</p>	<ul style="list-style-type: none"> • identify and address the triggers and underlying emotion or feelings, • simplify the task and communication, • ask a 'why?' question to understand and reduce repetitive questioning, • if an explanation doesn't help, a distraction or activity may diffuse the situation, • remain calm and use a low tone of voice, • state things in positive terms – constantly saying 'no'; or using commands increases resistance, • don't force or restrain the person with dementia.
<p>Disinhibited behaviour, by understanding why a person with dementia is behaving in this way (for example due to memory loss, disorientation or discomfort), we can help avoid triggers. A person with dementia may have forgotten where they are, how to dress, the importance of being dressed, where the bathroom is and how to use it; they may have confused the identity of a person; they may be feeling too hot or cold or their clothes may be too tight or itchy; or are confused about the time of day and what they should be doing.</p>	<ul style="list-style-type: none"> • respond with patience and in a gentle, matter-of-fact manner, • don't over-react; remember it is part of the condition, • reassure and comfort the person who may be anxious, • gently remind the person with dementia that the behaviour may be inappropriate, • lead them gently to a private place, • provide clothing that is more comfortable, • distract the person with dementia by providing something else to do.

6.2 Occupational / meaningful activities

The role of the relative is to help the person with dementia to start different activities that they participate in and can plan certain tasks that help appropriately to fill in and structure the days. We can include the person with dementia in everyday activities, such as cleaning, cooking and taking care of their own personal hygiene. All tasks should take place in previously established order and in the environment that they know. Let it be appropriate for individuals cognitive and physical capabilities. When designing the activities don't think about what the person cannot do, try and focus on what they can still do. Often the people with dementia may start tasks that they haven't been doing before. We should accept such activities and let them participate in such activities. It is important that the person gets acquainted with something and remains active for a longer time. Effective activities for the person can easily be found through trial and error. What is most important is that the person has something to do in order for them to remain active for longer. The final result is not important, what matters is participation and satisfaction. When due to the progression of the disease the capabilities fall, we can give them less difficult tasks or only parts of the tasks.

Activities of daily living refer to activities that people carry out every day as part of their established daily routines. There are two broad categories according to their purposes, the first is Basic activities of daily living, while the second is Instrumental activities of daily living. Both basic and instrumental activities of daily living can be incorporated into activity-focused dementia care with many positive benefits. Daily routines can be helpful for both — the caregiver — and the person living with Alzheimer's. A planned day allows you to spend less time trying to figure out what to do, and more time on activities that provide meaning and enjoyment. Examples of basic every day activities include combing one's hair, shaving, and brushing one's teeth. So if a comb is placed in the hand of a woman with severe dementia, it may automatically cause the act of combing her hair, because it is such a habitual action. Another example is dressing. How we dress expresses a lot about who we are as individuals and what we do in our lives. It is important that people with dementia are allowed to participate in dressing themselves to the fullest extent possible. It is also important that what they wear reflects their personal preferences and, if possible, unique identities.

Instrumental activities of daily living (IADL), are directed outward toward our living environments. IADLs include caring for our homes and other people. Examples include preparing food, washing dishes, raking leaves, sweeping the floor, and keeping track of money. People with dementia can often still participate in activities like these, because such activities are very familiar and use repetitive, over-learned patterns of movement. Even if a woman with dementia can no longer plan a meal or assemble ingredients to cook, she might still be able to stir ingredients or peel potatoes using automatic patterns of movement. A man who can no longer manage his money may still enjoy sorting change. Including people in chores like raking leaves, sweeping the floor, wiping the table, drying dishes, or folding towels may be enjoyable and also provide a sense of usefulness. These repetitive activities provide an opportunity for those with dementia to feel productive and useful.

Example of allocating activities preparing lunch:

- choose the menu,
- buy in the store,
- packing up the bought groceries,
- cleaning and cutting ingredients,

- placing the groceries in the cooking pans,
- steering dishes,
- setting the temperature of the oven,
- preparing plates, cutlery and napkins,
- taking the food back to the table
- lunch,
- tidying up the table,
- placing the dishes in the dishwasher,
- turning on the dishwasher,
- taking out and wiping out the dishes and cutlery,
- rest.

6.3 Day-to-day activities: Structuring a day - basic hygiene, nutrition and sleep

A person with Alzheimer's or other progressive dementia will eventually need a caregiver's assistance to organize the day. Structured and pleasant activities can often reduce agitation and improve mood. Planning activities for a person with dementia works best when you continually explore, experiment and adjust. Taking on the task of being responsible for activities of somebody else can be both physically and emotionally draining. Plan and take part in activities that you yourself enjoy as well. More that you will be satisfied yourself the better will be for everyone. People with dementia need organisation and structure.

Before Making a Plan, Consider

- The person's likes, dislikes, strengths, abilities and interests,
- How the person used to structure his or her day? ,
- What times of day the person functions the best? ,
- Ample time for meals, bathing and dressing,
- Regular times for waking up and going to bed (especially helpful if the person with dementia experiences sleep issues),
- Make sure to allow for flexibility within your daily routine for spontaneous activities.

As Alzheimer's disease progresses, the abilities of a person with dementia will change. With creativity, flexibility and problem solving, you'll be able to adapt your daily routine to support these changes.

Checklist of Daily Activities to Consider:

- Household chores: help in the kitchen, washing dishes, vacuuming, sweeping the floor, cleaning dust doing laundry, cleaning the bathroom, taking out the trash or bringing mail.
- Mealtimes: help in buying groceries, preparing meals or baking.
- Personal care - bathing, showering, personal hygiene, dressing, eating, brushing teeth, cleaning nails and brushing hair.
- Creative activities (music, art, crafts),
- Spontaneous (visiting friends),
- Intellectual (reading, puzzles),

- Physical: doing sports, passing the ball, bowling or fishing, everything that the person liked to do before the disease,
- Social and family activities: walking and hanging out with family and friends, participating in various family events,
- Memory activities: photo albums, movies, memory cards, cross-puzzles, moving the coin from one box to another..,
- Spiritual or religious activities: participating in mass, listening to a preacher etc.,
- Rest: rest after lunch, sitting and relaxing, listening to music.
-

6.3.1 Writing a plan

When thinking about how to organize the day, consider:

- Which activities work best? Which don't? Why? (Keep in mind that the success of an activity can vary from day-to-day.),
- Are there times when there is too much going on or too little to do? ,
- Were spontaneous activities enjoyable or did they create anxiety and confusion ?,
- Don't be concerned about filling every minute with an activity. The person with Alzheimer's needs a balance of activity and rest, and may need more frequent breaks and varied tasks.

Daily plan example (for early- to middle-stages of the disease):

Morning

- Wash, brush teeth, get dressed,
- Prepare and eat breakfast,
- Have a conversation over coffee,
- Discuss the newspaper, try a craft project, reminisce about old photos,
- Take a break, have some quiet time,
- Do some chores together,
- Take a walk, play an active game.
-

Afternoon

- Prepare and eat lunch, read mail, wash dishes,
- Listen to music, do crossword puzzles, watch TV,
- Do some gardening, take a walk, visit a friend,
- Take a short break or nap.

Evening

- Prepare and eat dinner, clean up the kitchen,
- Reminisce over coffee and dessert,
- Play cards, watch a movie, give a massage,
- Take a bath, get ready for bed, read a book.

6.3.2 How to adapt the environment / home to be dementia friendly

Taking care of safety is especially important at the start and middle part of the dementia. To prevent harm, it is important to take away all the potential danger in around the person with dementia and discretely control the feelings of the person with dementia. Having the balance between the independence and dependence is crucial. Home safety is important for everyone, but this is especially true if you're caring for someone with Alzheimer's disease or a related dementia. A throw rug or a stray toy on the steps could easily cause a fall or injury. People with dementia often forget to eat and drink and can become dehydrated as a result.

The changes that can lead to reduced safety in the environment are

- Limited judgement: they don't know how to use kitchen appliances or other tools,
- Inappropriate dressing and footwear: inappropriate footwear can increase the likelihood of falling,
- Problems in communication: it has difficulties of communication; it does not understand the spoken or written instructions,
- Problems in time and space orientation: the person with dementia can easily get lost, even in front of their own house they may not be able to recognise their own neighbourhood,
- Behavioural changes: the person with dementia can easily become agitated, can get confused or become aggressive and suspicious,
- Reduction in body functions: they may often have problems with balance, they need a trolley or a walker,
- Reduction in senses: the person with dementia can have changes in eyesight, hearing, smell, sensing the temperature or sensing the depth.

The taking care of safety is especially important at the early or middle stage of the dementia. This can help at prevent injuries, it is important to help to reduce the potential danger in the environment and discretely ensure the feeling of the person with dementia. Balance between the independence, privacy, and safety is necessary to be established.

Make sure that safety in the environment is established

- Watch for the risk of choking,
- Look for ways how to increase safety in home that the person with dementia does not wander away from home, turn on the stove and forget to turn it off, etc,
- Look for ways how to prevent falls and improve bathroom safety.

To reduce the confusion of people with dementia

- Have familiar objects and people around. Family photo albums can be useful,
- Keep always lights on,
- Use reminders, notes, lists of routine tasks or directions for daily activities,
- Stick to a simple activity schedule,
- Talk about current events.

Being home alone at a certain point in time will not be safe anymore. This moment may come with the person at a different time, which is why we must evaluate when it is important to make ends meet. This is why we must be the ones that evaluate when it is important to take appropriate measures. For the relatives of the person with

dementia it's important for the person with dementia does not understand why it is not supposed to live alone. It stands up to any idea that anyone should watch over her or declines going into daily center. In such case, we must remain to have enough caution that the person with dementia still keeps their own autonomy. It's important to know what words to choose. We avoid any words that would say that "somebody must take care of you", "you can't stay at home alone" and "you can't take care of yourself". Rather we try to distract them or motivate them for something else.

6.3.3 Medication

The person with dementia at the start of the disease cannot take the prescribed medication anymore. This is why they may forget when they must take certain medication or they may take double or more medication. Taking care of the medication falls onto relatives or caregivers. Medications should be placed in a safe place or locked. This is something we do most discretely, so that the person does not feel sad, angry or incompetent.

6.3.4 Evaluating home safety

Home must be prepared for living with the person with dementia in a way that is safe especially in the later stages of disease, where problems with balance, coordination and space judgment may occur. Changes in the adjustment of the environment do not let them be over problematic, as this can cause confusion so that the person may want to go home while they are already home. Spaces should be neutral colours, we may avoid any patterns.

In the bathroom

- Install a shower chair and grab bars,
- Address slippery surfaces,
- Use a faucet cover in the bathtub,
- Lock up potentially hazardous products or electrical appliances,
- Reduce water temperature,
- Remove door locks.

In the kitchen

- Prevent access to potentially dangerous appliances,
- Remove artificial fruits or vegetables or food-shaped magnets,
- In the bedroom,
- Install a monitoring device,
- Take caution when using heating devices.

In the main living areas

- Avoid clutter,
- Mark glass doors, windows and furniture,
- Take caution when using fireplaces.

In the laundry room

- Lock up potentially hazardous products,
- Prevent access to the washer and dryer.

In the garage, shed and basement

- Lock up potentially dangerous items,
- Lock all vehicles.

To ensure safety outdoors

- Check exits,
- Keep steps safe,
- Restrict access to the pool,
- Avoid clutter,
- Safely store fuel sources.

In addition, consider taking these safety precautions throughout your home

- Prepare for emergencies,
- Use night lights,
- Treat slippery or uneven surfaces,
- Adjust the home phone and voice mail settings,
- Keep stairs safe,
- Install smoke alarms and carbon monoxide detectors,
- Check the locks,
- Address outlets and electrical cords,
- Keep computer equipment out of the way,
- You can buy many products or gadgets necessary for home safety in hardware, electronics, medical supply and children's stores. If you need help making changes to your home, enlist friends, a home safety professional or a community organization.

Remember, paying attention to home safety can help the person with dementia maintain his or her independence — and ease the stress of caregiving. In some communities, dementia related support groups may be available. Family counselling can help family members cope with home care. Advance directives, power of attorney and other legal actions may make it easier to decide on the care of the person with dementia.

6.3.5 Driving

Immediately after the diagnosis people with dementia should stop driving. This kind of decision is better taken, if all the relatives are uniform in their decision. With the person with dementia have a normal conversation and understand that this is taking away their freedom and therefore it may be difficult to accept this. Possibly the person with dementia may forget about driving or adjust to the fact that they are not driving. In this case if they insist on driving we hide the car or prevent the car from driving. It is also advisable to consult with the medical doctor or other health professional.

Long term care: A person with dementia can need monitoring or help at home or in an institution. Some options may include

- Adult day care,
- Nursing homes,
- In-home care.

7 Unit 6: Promoting Better Care

7.1 Pharmacological and Non-Pharmacological Approaches / Strategies

Before starting to read this chapter, take some time to listen to the podcast and try out the proposed exercise.

8.1.1. Pharmacological Approach to Alzheimer's Disease

Although drug treatments used in Alzheimer's disease do not completely eliminate the disease, they have been developed to slow down the progressive symptoms. Although the symptoms do not disappear in diseases that cause dementia, the drugs used have positive effects on the course of the disease.

Drugs Used in Treatment

Acetylcholinesterase inhibitors and memantine, an NMDA (N-methyl-D-aspartate) receptor antagonist, are molecules that have been shown to be effective in the treatment of Alzheimer's disease with evidence-based medical knowledge. Acetylcholinesterase inhibitors are indicated for the treatment of mild to moderate Alzheimer's disease and memantine is indicated for the treatment of moderate to severe Alzheimer's disease.

1-Cholinesterase Inhibitors

- Tacrine,
- Donepezil HCl,
- Rivastigmine tartrate,
- Galantamine.

2-NMDA receptor antagonist

- Memantine.

Cholinesterase Inhibitors

Acetylcholine is one of the most important neurotransmitters for memory functions. Acetylcholinesterase enzyme inhibitors prevent the degradation of acetylcholine and prolong its effect on cholinergic synapses by increasing the amount of acetylcholine in the neuronal synapse. Acetylcholinesterase inhibitors used in our country and in the world are donepezil, rivastigmine and galantamine. The most common side effects are nausea, vomiting, diarrhea and weight loss. It also has side effects such as muscle cramps, frequent urination, headache, bradycardia, cardiac conduction disorders, sleep disorders and agitation. In general, the incidence of side effects increases as the effective doses are increased with acetylcholinesterase inhibitors. In order to avoid side effects in patients, drugs should be used as a full and in the morning hours, and the titration time should be taken into account (*Vademecum Online*, 2022).

For the treatment of Alzheimer's Disease, first tacrine, and later donepezil, rivastigmine and galantamine came into use. While tacrine and rivastigmine inhibit both acetylcholinesterase and butyrylcholinesterase, donepezil and galantamine specifically inhibit acetylcholinesterase.

Tacrine hydrochloride: It is a cholinesterase (ChE) inhibitor. It is the first drug approved for improvement in cognitive symptoms (memory, attention, reasoning, speech, and ability to do simple tasks) associated with

Alzheimer's disease. In a recent meta-analysis of 12 studies involving 1984 patients treated with tacrine for up to 1 year, Mini-Mental As measured by the Status Test (MMSE) and Clinical Global Impression scale, tacrinin has been shown to reduce cognitive performance deterioration in patients during the first 3 months of treatment. In clinical studies conducted so far, there is no evidence that tacrine slows the long-term course of Alzheimer's disease, and there is no data yet showing that ChE-inhibitor treatment provides a sustained improvement in the patient's quality of life.

In a large and uncontrolled study, it was shown that hospitalization may be delayed in patients receiving tacrine at doses of 80-120 mg/day or higher. Clinical efficacy is often limited by the patient's ability to tolerate tacrine doses higher than 120 mg/day. The use of tacrine requires monitoring of liver function because of the risk of transaminase elevation and hepatocellular damage. Tacrine for the treatment of mild to moderate Alzheimer's disease Tacrine was approved by the FDA in September 1993 for the treatment of mild to moderate Alzheimer's disease. Tacrine slows progression, but treatment should be started at an early stage. Its effects become evident in the 3rd month and disappear 4-6 weeks after the drug is discontinued.

Donepezil HCl: It is indicated for the treatment of mild to moderate dementia in Alzheimer's disease. The most common adverse effects are diarrhea, muscle cramps, weakness, nausea, vomiting and insomnia.

Rivastigmine tartrate is indicated for the symptomatic treatment of mild to moderate dementia in Alzheimer's disease or accompanying Parkinson's disease. Gastrointestinal diseases such as nausea, vomiting and diarrhea, weight loss are among the common side effects (Kurz & Grimmer, 2017).

Galantamine is indicated for the symptomatic treatment of mild to moderate Alzheimer's dementia associated with cerebrovascular disease. Weight loss can be observed in Alzheimer's patients during treatment with cholinesterase inhibitors, including galantamine (*Vademecum Online*, 2022).

[NMDA \(N-methyl-D-aspartate\) Receptor Antagonist](#)

In Alzheimer's disease, glutamate causes excessive calcium entry into the cell via NMDA receptors, creating a toxic effect on neurons. Memantine, another molecule used in the treatment of Alzheimer's, reduces glutamate by relatively weak blocking of NMDA receptors and prevents the pathological entry of calcium into the cell. Memantine is effective in the cognitive symptoms of moderate-to-severe Alzheimer's disease and activities of daily living. Memantine may also have beneficial effects on behavioral symptoms. There are data that it especially reduces agitation, in patients. Memantine can be used as a single dose of 20mg/day. Side effects such as headache, confusion, vertigo and hallucinations may be seen rarely in patients using memantine. Since memantine is excreted by the kidney, it should be used with caution in patients with renal failure and the dose should be reduced if necessary.

Neuropsychiatric-behavioral symptoms such as depression, hallucinations, delusions, insomnia, mania, agitation, apathy and anxiety are common in Alzheimer's patients. In addition to the drugs used for cognitive symptoms, various drugs, especially antidepressants and antipsychotics, can be used for these complaints. Care should be taken when choosing drugs for behavioral symptoms in Alzheimer's patients. Drugs with anticholinergic effects, such as tricyclic antidepressants, should not be preferred in the treatment of depression. Because of their potential for side effects, typical neuroleptics and benzodiazepines should not be used unless absolutely necessary. Drugs to be used for behavioral symptoms should be started at low doses and increased slowly. Vascular dementia is the second most common type of dementia, and Alzheimer's disease coexistence (mixed dementia) is common. The first goal of treatment in vascular dementia is to prevent new vascular lesions and

possible complications. Therefore, antiaggregant, anticoagulant, antihypertensive drugs should be used according to the underlying cause.

Adukanumab

It is an antibody targeting amyloid beta, used intravenously in the treatment of adult Alzheimer's patients. Approved under the FDA's Accelerated Approval Program. This type of approval allows patients to have earlier access to drugs in severe disease, although the overall clinical benefit is somewhat uncertain when it comes to clinical utility of the drug relative to a secondary evaluation parameter. The secondary parameter that led adukanumab to receive expedited approval in June 2021 was the reduction of amyloid beta plaques in patients. The efficiency of aducanumab was evaluated in two Phase 3 clinical studies (ENGAGE and EMERGE) and one dose-determining Phase 1b studies (PRIME). In these studies, ENGAGE, EMERGE, and PRIME, aducanumab reduced amyloid beta plaques by 59%, 71%, and 61%, respectively. Participants in clinical studies are mostly early-stage Alzheimer's patients.

Continuity of approval for this indication depends on confirmation of clinical benefit (eg, slowing disease progression) by studies. Safety concerns with the drug are the risk of serious hypersensitivity reactions and imaging abnormalities due to amyloid plaques (ARIA). These abnormalities appear as temporary swellings in brain areas that usually resolve over time and do not cause symptoms. Some patients may experience symptoms such as headache, confusion, dizziness, blurred vision or nausea (*RxMediaPharma*[®], 2022). This drug is currently only used in the USA.

Drugs Used in the Treatment of Behavioral Symptoms

Antidepressants: Depressive mood disorder, decreased motivation (Citalopram, Fluoxetine, Paroxetine, Sertraline, Mirtazapine etc.)

Neuroleptics, Antipsychotics (Risperidone, Aripiprazole, Clozapine, Quetiapine etc.)

Other Medicines

- Gingko biloba,
- Piracetam,
- Antioxidants, Some vitamins.

Vitamins

If there is no detected vitamin deficiency, extra vitamins will not be beneficial. When vitamins exceed the targeted level, they can be harmful by having the opposite side effect. However, if there is a detected vitamin deficiency, then replacement therapy and treatments to correct the vitamin deficiency will be given.

Herbal Product Use or Natural Products

These products have no proven efficacy. These products may also interact with prescription drugs. This can cause serious side effects or reduce the effectiveness of the drugs used. Therefore, the physician should be consulted when using these products.

Gingko biloba is the most studied plant extract in mild to moderate Alzheimer's type dementia, vascular dementia and mixed forms of dementia. The level of evidence for their usefulness is low.

Piracetam is a mental behavioral defect due to aging, excluding the deficiencies in recalling, retaining memories, concentrating attention, sleep disorders, vigilance deficiencies, and established dementias, such as Pick's and Alzheimer's diseases. Agitation, irritability, and weight gain may occur at the beginning of treatment (Hanagasi, 2019; Winslow et al., 2011)

What Should We Pay Attention to When Using Drugs;

It would be helpful to prepare a list of drugs. In this list;

- Names of drugs,
- Doses of drugs,
- The time of administration of the drugs and how they will be administered (hungry/full) should be included.

Thus, the patient's compliance with drug treatment will increase. Health problems caused by misuse of drugs will be prevented

What should we do when the patient does not want to take his medication?

- Explain why the medicine is given. The patient may think that you are giving the drug to poison him, as he may be more suspicious and anxious at some times,
- If your patient has difficulty in using the drug and the patient refuses to use the drug; In consultation with your doctor and pharmacist, you can mix the drugs with some foods and give them to your patient. However, you should consult your doctor or pharmacist as medications and foods may interact. The foods consumed during drug use may have reducing or increasing effects on the effects of drugs. (The food-drug interaction is when the nutrients taken together with the drugs used change the effect of the drugs on the body.),
- Make sure your patient is taking their medicine,
- If your patient continues to refuse to take their medication, different forms of medication may be preferred. Consult your doctor about this.
- Medications should not be stopped abruptly, and should be acted upon in line with the direction of the physician following the patient.

These drugs are drugs that are used chronically. In cases where medication is required in case of a different disease, we must inform our doctor about these drugs. Because drug interactions can reduce the patient's response to treatment, they can have serious undesirable effects that require hospitalization and sometimes even death. Considering that Alzheimer's disease and dementia are age-related diseases, both age-related physiological changes and the high number of prescribed drugs make these patients more susceptible to drug interactions.

If the patient has a complaint or a negative situation when a new drug is added to the treatment or any change is made in the previous treatment plan, we must inform the doctor about the subject (Türkiye İlaç ve Tıbbi Cihaz Kurumu, 2022).

Most Common Side Effects

Gastric Side effects: nausea, vomiting, abdominal pain, etc. It is frequently seen in the early period and in the periods when the dose of the drug is increased. It is expected that the complaints will regress within a week or

two from the start of the treatment. If there is no regression at the end of this period, it may be necessary to consult your doctor. If there is a suggestion for the management of gastric side effects in this process, it should be added.

Acetylcholinesterase Inhibitors (Donepezil HCl, Rivastigmine tartrate, Galantamine) These drugs are generally recommended to be used in the morning by the physician as they cause deterioration of night sleep quality and nightmares.

On the other hand, NMDA receptor agonist (Memantine) may occasionally cause drowsiness. In these cases, taking it in the evening on a full stomach will prevent being asleep during the day and increase the quality of sleep at night.

Vaccine in Alzheimer's Disease

In Alzheimer's Disease, there are two important accumulations in the brain. These are Amyloid Beta plaques and neurofibrillary tangles containing Tau protein. Today, vaccines are being developed against the accumulation of these two substances in the brain and these vaccines are being tested. Vaccine studies aim to remove these substances from a very early period. Unfortunately, when the disease reaches a certain stage, the removal of these substances from the brain is not effective in the recovery of the disease. Today, many studies aim to remove these substances at an early stage or before the disease starts at all. We will find out in the coming years whether these vaccines will be useful.

Are there any medications that Alzheimer's patients should not use?

Alzheimer's drugs are drugs that are used chronically. If a different drug is to be used, the relevant doctor should be informed about it, as there may be interactions.

8.1.2. Nonpharmacological Approaches in Alzheimer Patients

In Alzheimer's, non-drug treatment methods applied in addition to drug treatment provide cognitive protection and can delay the emergence of moderate and severe symptoms of the disease. Non-drug treatments are patient-centered, treatments aimed at supporting individuals rather than forcing them and focusing on their deficiencies.

Non-drug treatment methods should exercise/protect cognitive skills, improve/stabilize daily activities, and support mental health. It helps to prevent difficult behavior such as restlessness and irritability and to improve physical condition. Non-drug treatment of dementia also includes supporting relatives and reducing their share of the burden. When patients feel good, care personnel and family members are also positively affected by this situation (Flamme, 2022).

Some of the non-pharmacological treatment methods can be written by the doctor and provided free of charge by the social security institutions. This applies to physiotherapy (patient gymnastics), occupational therapy, logopedia and behavioral therapy.

Which Treatments are Available?

It ranges from psychotherapeutic treatments in the early stages to specialized forms of communication (eg validation) or sensory stimulation in the later stages of the disease. Some of these are applied by specialists, while others can be used by family members or caregivers and integrated into daily life. All therapeutic interventions are individualized and should be modified according to changing circumstances over the course of the disease.

Treatments can only be successful when personal skills, preferences, needs, motivation and resource biographical experiences are taken into account. In the meantime, cognitive overload (but also over-underloading) should be avoided as much as possible. Consciously promoting existing skills and providing the patient with the opportunity for subjective experiences of success should be the focus. In deciding which treatment is appropriate, it should be taken into account that dementia affects all areas of physical/psychic and social life and that a single method cannot be effective, and relevant professionals should be cooperated.

Due to the variety of different treatments, only a brief overview of important approaches can be presented here (Flamme, 2022).

Psychotherapeutic Approaches

Psychotherapy

It can support a person with dementia in the early stages of the disease in accepting and overcoming the diagnosis. Psychotherapy can also be beneficial for family members, eg. in chronic overload, depressive symptoms, or increased helplessness to the effects of the illness on one's life. If the behavior of people with dementia is very disturbing and burdensome for other people, behavior therapy can benefit from behavior therapy, which can change the thoughts, approaches, and evaluations that affect their behavior and feelings. This technique uses positive incentives (rewards) to change behavior. At the beginning of the disease process, the patient is worked with, then the patient's relatives are guided (eg, supporting independent behavior during food intake or body care).

Psychoeducation

Through the "biopsychosocial disease model", patients and their relatives are provided with individual and situational information about the cause, symptoms, course, results, beneficial and harmful factors of the disease. This information helps the patient and family members better understand the diagnosis, classify the symptoms, and actively cope with the illness. Psychoeducation can be applied individually or in groups.

Help Groups

Self-help groups, usually initiated and accompanied by the staff of the counseling centres, are primarily for family members and, in individual cases, for patients. Mutual "morale" support is often at the forefront, but information exchange and social support through the group are also important.

Relaxation Exercises

Jacobson progressive muscle relaxation techniques are suitable for people with dementia. Because it can be learned easily with professional guidance and can be applied independently (supported by family members or care staff) at home (Deutschen Alzheimer Gesellschaft, 2016; Flamme, 2022).

Other Nonpharmacological Approaches

Memory or Reminiscence Therapy (Memory Training)

Individual or group conversations about previous experiences and lived events are called reminder therapy. Its purpose is to stimulate the individual mentally and improve his mood. Memories are revived with the help of frequently used objects (eg, household items, clothes, photographs, stories, music, etc.), personal important events and experiences are talked about, while consciously recalling memories in the distant memory is ensured. This often works because individuals with dementia often retain long-term memories of their childhood and youth, while short-term memory no longer works very well. Therefore, this treatment is also suitable for patients with severe dementia.

Cognitive activation applied in a familiar group is more appropriate in the middle stages. What is important here is that the exercises are carried out in a relaxed atmosphere and that the participants enjoy it. The dynamic that occurs within the group also strengthens the sense of togetherness and self (Duru Aşiret & Kapucu, 2016).

The Reality Orientation Training

Reality Orientation Strategies

- Talk about directions, including time of day, date and season.
- Use the person's name often.
- Discuss current events.
- Look at clocks and calendars.
- Place signs and labels on doors and cabinets.
- Ask questions about photos or other embellishments (Heerema, 2014).

Ergotherapy

The aim of ergotherapy (occupational therapy) is to preserve and support everyday skills. It is especially useful in the early and middle stages of the disease. With ergotherapy, they learn to solve practical problems, create a daily routine, and benefit from reminders. If the disease is at a more advanced stage, occupational therapy can contribute to supporting body image and movement. Ergotherapists can also provide information to patients and family members about housing adaptations (Deutschen Alzheimer Gesellschaft, 2016; Flamme, 2022).

Logopedia

Dementia can negatively affect speaking and communication skills. Logopedia can improve word finding, pronunciation and speech comprehension, especially in beginning people. When swallowing disorders occur, logopedia can assist with safe food intake (Deutschen Alzheimer Gesellschaft, 2016).

Physical Activity and Exercise

Regular movement and moderate sports activities are not only good for our body and soul, but also have positive effects on cognitive skills and maintaining daily competencies. Studies have shown that Alzheimer's patients who exercise have less depression and behavioral problems, better quality sleep, and improvement in memory and social skills. In order for the exercise to be suitable for the period of the disease, a personalized exercise program should be arranged in consultation with a specialist doctor.

People who like to go for a walk, bike ride, swim or go to a fitness club should continue these activities for as long as possible, preferably with family members, friends or acquaintances. Physiotherapists can consciously support the patient in active mobility individually or in a group if physical function or movement restrictions are present (ATICI, 2019). Suggestions to start an exercise program for a person with dementia include;

- Talk with the person's doctor and organise a full medical check-up. Other health conditions, such as arthritis or high blood pressure, may limit the types of exercises the person with dementia can safely perform,
- A physiotherapist can design an exercise program that takes the person's current health and abilities into account,
- Start slowly. For example, perhaps five minutes of continuous exercise is all the person can manage at first. Over a period of months, add one extra minute at a time until the person can comfortably exercise for 30 minutes,
- Demonstrate the activity yourself and ask the person to follow your lead,
- Boredom kills off motivation, so mix up the activities to keep it interesting.

Keeping Track of Exercise and Physical Activity; It is important to keep track of exercise and physical activity progress. Recording of walking distance, exercise period, weight training repetition to see the progress of person with dementia needs to be done. An increase in the distance walked in 5 minutes indicates improvement in aerobic capacity and increased muscular endurance (Uysal, 2020).

Suggestions to Improve Safety Include;

- For outside activities, make sure the person is in a safe environment for physical activities,
- Use weight machines rather than dumbbells or barbells that can be dropped,
- If the person can still talk while exercising, they're in a comfortable aerobic state. Keep the conversation flowing to monitor how puffed they're getting. Slow it down if they can't talk without gasping,
- For outdoor activities, make sure the person is sun smart – cover up with clothing and a hat, and apply sunscreen to all exposed areas of their skin,
- Ensure that the person drinks plenty of water before, during and after exercise,
- If the person complains of feeling dizzy or faint, or says they have any kind of pain, stop the activity and talk to their doctor.

Exercise and physical activity can have lots of benefits for people with mild to moderate dementia. It can help regulate their sleep and prevent restlessness and sleeplessness in the evening. Some suggestions include easier exercises, tai-chi dancing, swimming, walking, gardening and housework – such as vacuuming and folding laundry.

In moderate to late stages of dementia, support and encouragement from family, carers and service providers is important to ensure that an exercise program is maintained. Accessing a structured exercise program with trained staff and using family, friends and volunteers can help to ensure this (Mehlig et al., 2014).

Suggested Exercises Include;

- When getting up or going to bed, shuffle along the edge of the bed, in the sitting position, from one end of the bed to the other. This helps exercise the muscles needed for standing up from a chair,

- Balance in a standing position. This can be done holding on to a support if necessary. This exercise helps with balance and posture and can form part of everyday activities, for example when showering or doing the washing up,
- Sit unsupported for a few minutes each day. This exercise helps to strengthen the stomach and back muscles used to support posture. This activity should always be carried out with someone else present as there is a risk of falling,
- Lie as flat as possible on the bed for 20-30 minutes each day, trying to reduce the gap between the curve of the back and the mattress. This allows for a good stretch, strengthens abdominal muscles and gives the neck muscles a chance to relax,
- Stand up and move about regularly. Moving regularly helps to keep leg muscles strong and maintain good balance.

Physiotherapy

Physical coordination be improved through physiotherapy. The aim is to gradually improve and maintain the patient's health through endurance, strength, and coordination exercises. Physiotherapy can support them to move safely and prevent falls during this time. A physiotherapist can work with the person with dementia and their carers to encourage and promote physical activity and maintain their mobility and independence for as long as possible. Physical therapists can not only help reduce symptoms in patients with respiratory diseases through breathing and airway clearance techniques but with the use of gradually progressing exercises they can improve patient's quality of life significantly.

Therapy With Music

Various studies have shown that music has positive effects on the nervous and neurological systems of Alzheimer's patients, resulting in meaningful responses in the emotions and thoughts of the patients; It shows that it regulates physiological functions such as blood pressure and respiratory rhythm and establishes the oxygen and blood supply balance in the brain. In music therapy, it is the listening, singing or playing of songs and musical pieces within the framework of a therapeutic relationship. This can be done individually as well as in a group.

It is stated that while tempo music types containing positive words have positive effects on patients, slower and relaxing music reduces emotional turbulence and suppresses anger in patients. Particular attention should be paid to ensure that the music played is not loud. Trying another song by observing the patient's reactions to the song being played will have a positive effect on the patient.

It is preferable to refer to "Old" music that is biographically significant. Patients in the last stage of the disease may be asked to make a guess by listening to music they know very well, by asking the words of the song and who is singing it. Thanks to music, patients with severe dementia who have difficulty in expressing themselves by speaking can also be reached. It can revive memories, express emotions, make creativity possible.

Art Therapy

Art therapy is possible in many forms, primarily drawing, painting and object design. Art and music therapy is offered professionally, but family members and/or caregivers can support creativity and emotional expression. Creative expressions enable them to interact actively with their environment and increase their self-confidence.

Ambient therapy

Ambient therapy considers the social and organizational environment of a person with dementia, such as the architecture and furnishings of spaces. The aim here is to adapt this environment to suit the declining abilities of the human being. The patient's home is modified and designed so that he can adapt as well as possible and move safely. This can reduce stress and improve quality of life.

Validation Therapy

Validation therapy imparting respect to the person, their feelings and their beliefs is the basis of non-drug treatment methods. Validation therapy is a method of therapeutic communication which can be used to define the types of actions or behaviors one should use when communicating with a person who has dementia

Memory Exercise

Memory exercise, also known as cognitive exercise or brain performance exercise, aims to protect and support mental (cognitive) skills such as remembering, thinking, and attention. The ability to remember, think, concentrate, etc. The exercises are done by playing and often in groups. Activities should be daily and connected with movement. Brain performance exercise is especially suitable for people suffering from mild to moderate dementia.

In memory exercise, attention should be paid to the cultural characteristics and education level of the person. Recognizing concepts, matching socks, which object is good for what, seasonal fruits and vegetables, clock game, sequencing events, memory cards, animals and their offspring, animals and their places, testing knowledge on small topics, doing and solving puzzles together, improvising Examples of memory exercises are trying computer games that help improve cognitive functions, playing bingo and bingo games, playing card matching games, making jokes, creating a writing tray, dolls, playing with plushies, and memory exercises. They can participate in group intelligence games held in wellness centers and other establishments for memory exercises.(Deutschen Alzheimer Gesellschaft, 2016; Flamme, 2022)

Special Therapies in Severe Dementia

Confirmation is a common intervention measure often used in care and a treatment that is respectful in dealing with people with dementia. The goal here is to create an atmosphere of safety, a sense of protection and significance for patients by first carefully listening and acknowledging their needs and feelings, and then verbally or nonverbally reflecting (affirmation). Thanks to this special form of communication, positive emotions come to the fore and negative emotions are reduced.

Bodily therapies Especially in late stages, patients may perceive themselves and their environment in a very limited way. With the help of sensory treatment methods such as basal stimulation, snoezelen, aromatherapy, massage and targeted touches, all senses (touch, hearing, sight, taste, smell) can be addressed, especially through contact and movement. Supporting relatives and reducing their burden (Flamme, 2022).

7.2 Challenges of the Different Phases of the Disease and Uncommon Situations

Dementia can lead to behaviour changes, which may cause distress for the person with dementia and place added pressure on family and carers. Some changed behaviours-can be difficult to deal with for carers.

Nonpharmacologic interventions are recommended as the initial strategy for managing problematic behaviors. Because limiting pharmacological interventions has an important role in minimizing drug interactions and side effects of drugs.

Changes in behaviour may include aggression, distress, agitation, hallucinations and delusions, restlessness, hoarding, repeating the same question or activity over and over again, wandering, sleep disturbance, eating problems. The severity may be different for each person in different stages of dementia.

Potential causes for behavioral challenges and negative behavior maybe related to

- Physical pain or discomfort: Illnesses, medication, hunger or thirst,
- Overstimulation: Loud noises or a busy environment,
- Unfamiliar surroundings: New places or the inability to recognize home,
- Complicated tasks: Difficulty with activities or chores,
- Frustrating interactions: Inability to communicate effectively.

Common dementia-related behaviors

Aggression

Aggression may include shouting or screaming, verbal abuse, and sometimes physical abuse. Aggression happens for no reason. If you deal with the causes, the behavior may stop.

Agitation/ Anxiety

Acts of agitation or anxiety have a wide variety of causes. This might involve screaming, shouting, being stubborn, or acting uncontrollably. These aggressive outbursts can be scary and difficult for caregivers to handle.

It can help to learn what triggers this response by considering the person's surroundings, time of day and what has just occurred, and evaluating potential sources of pain, hunger, need for sleep and sudden changes.

How to Respond;

- Check for pain. Pain can often trigger anxiety or agitation. Sources include being in an uncomfortable situation, injury, reaction to medication or a urinary tract infection,
- Listen to the frustration Find out what may be causing the anxiety and try to understand,
- Provide reassurance. Speak in calming tones and phrases. Let the individual know you're there for support,
- Involve the person in activities. Engage the person in art, music or other activities to promote relaxation,
- Modify the environment. Decrease noise and distractions or relocate the person,
- Find outlets for energy. The person may be looking for something to do. Take a walk,
- Effective lighting can help people with dementia. Lighting should be used in home to reduce the restlessness that may occur at night. Ray of light that strikes the mirror or glass should be blocked,
- Focus on the emotion. Rather than reacting to what the person is doing, respond to how he or she is feeling. For example, having the door locked can ensure patient safety, but it can cause frustration in the patient and cause aggressive behavior,

- Both the caregiver and the patient need to be safe. If the patient cannot be calmed down, you can get professional help (Alzheimer Association, 2015; Sadowsky & Galvin, 2012; Yalçın et al., 2005).

Forgetfulness and Confusion

A person with Alzheimer's disease may not recognize familiar people, places or things. He or she may forget relationships, call family members by other names or become confused about where home is. The purpose of common items, such as a pen or fork, may also be forgotten.

How to Respond;

- Stay calm. Not being recognized can be painful,
- Respond with a brief explanation. Instead, clarify with a simple explanation,
- Show photos and other reminders. Use photographs and other thought-provoking items to remind the person of important relationships and places,
- Maintain a Schedule As much as possible, encourage a regular routine of waking up, meals and going to bed,
- If the person with dementia is able to dress themselves, let him/her do it by himself/herself,
- Try not to take it personally. Alzheimer's causes forgetfulness, but your support and understanding will continue to be appreciated,
- Use calendars, clocks, labels, and newspapers for orientation to time,
- It's not advisable to make major changes to the home overnight. Labels and signs on cupboards and doors can be helpful (Sadowsky & Galvin, 2012; Schiff, 1990).

New Suspicions

Memory loss and confusion may cause a person with Alzheimer's to perceive things in new and unusual ways. Individuals may become suspicious of those around them, even accusing others of theft, infidelity or other improper behavior. Sometimes a person with the disease may misinterpret what he or she sees and hears.

How to Respond;

- Listen to what is troubling the person and try to be understanding. Then be reassuring, respond to the feeling and let the person know you care,
- Don't argue or try to convince. Allow the individual to express his or her ideas and acknowledge what was said,
- Offer a simple answer. Share your thoughts, but keep it simple. Lengthy explanations can be overwhelming,
- Switch the focus to another activity. Engage the individual in an activity or ask for help with a chore.
- Duplicate any lost items. If the person often searches for a specific item, have several available. For example, if the individual is always looking for his or her wallet, purchase two of the same kind,
- Check hearing and vision impairment. People with dementia often have physical difficulties including hearing and sight loss that can also cause problems with misinterpretation,
- Help the person with dementia take medicines safely. Information should be given to caregivers about the side effects of a particular drug (Alzheimer Association, 2015; Sarıkaya et al., 2017) .

Hoarding

People with dementia may often appear driven to search for something that they believe is missing, and to hoard things for safekeeping.

What to try?

- Learn the person's usual hiding places and check there first for missing items,
- Provide a drawer full of odds and ends for the person to sort out as this can satisfy the need to be busy,
- Make sure the person can find their way about, as an inability to recognise the environment may be adding to the problem of hoarding.

Repetitive Actions

A person with Alzheimer's disease may do or say something over and over again — like repeating a word, question or activity. The person may also pace or undo what has just been done. In most cases, he or she is likely looking for comfort, security and familiarity. These actions are rarely harmful, but can be stressful for the caregiver.

How to Respond;

- Look for a reason. Try to find out if there is a specific cause or trigger for the repetitive behavior,
- Focus on the emotion. Rather than reacting to what the person is doing, respond to how he or she is feeling,
- Turn the action or behavior into an activity. If the person is rubbing a hand across the table, provide a cloth and ask for help with dusting,
- Stay calm and be patient. Reassure the person with a calm voice and gentle touch,
- Provide an answer. Give the person the answer that he or she is looking for, even if you have to repeat it several times. It may help to write it down and post it in a prominent location,
- Engage the person in an activity. The individual may simply be bored and need a distraction. Engage the person in an activity like taking a walk or working on a puzzle,
- Use memory aids. Offer reminders like notes, photographs, clocks or calendars (Koca et al., 2017) .

Wandering and Getting Lost

It's common for a person with Alzheimer's to wander and become lost, and it can happen at any stage of the disease. They may try to go home when already there or attempt to recreate a familiar routine, such as going to school or work. As the disease progresses, the person with dementia will need increased supervision. At some point, it will no longer be safe to leave him or her alone.

How to Respond;

- Encourage activity. Keeping the person with Alzheimer's active and engaged can help discourage wandering behavior by reducing anxiety and restlessness,
- Involve the person in chores such as doing dishes, folding laundry or preparing dinner. If the person shows interest in getting out of the house, consider safe outdoor activities such as an accompanied walk or gardening,
- Inform others. Make sure friends, family and neighbors know that the person has Alzheimer's and that wandering may occur,

- Make the home safe. Install deadbolt or slide-bolt locks on exterior doors and limit access to potentially dangerous areas within the home,
- Use a medical alert bracelet to alert health professionals of your medical conditions in the case that they're unable to tell them (Sadowsky & Galvin, 2012).

Trouble with Sleep

People with dementia may experience changes in their sleep schedule or have problems sleeping. Although the exact cause is unknown, sleep changes result from the disease's impact on the brain.

How to Respond;

- Make a comfortable environment. The sleeping area should be at a comfortable temperature. Use nightlights and take other steps to keep the person safe, such as installing appropriate door and window locks,
- Maintain a Schedule as much as possible, encourage a regular routine of waking up, meals and going to bed,
- Manage naps. If the person has trouble sleeping at night, it can be helpful to limit daytime naps,
- Exercise. Try to include some type of exercise, as appropriate for the person, during the day. Physical activity may promote restfulness at night,
- Avoid stimulants. Reduce or avoid alcohol, caffeine and nicotine, which can all affect ability to sleep. Discourage watching television during periods of wakefulness at night, as it can be stimulating,
- Talk to a doctor. Discuss sleep disturbances with a doctor to help identify causes and possible solutions (Akyar, 2011; Sarıkaya et al., 2017).

Eating and Drinking for a Person with Dementia

A person with dementia may find eating difficult, lose interest in food, refuse to eat it or start to eat again because of loss of appetite, loss of memory and problems with judgement, side effect of drugs. Abnormal eating behaviors, eating problems, and dietary changes are present in most people with dementia (Koca et al., 2017).

Moving the patient to the dining room rather than the chair or bed where he/she sits all day will help him/her remember that he/she needs to eat. If there is no chance to eat in a separate room, the presence of a serving tray, cutlery will also help remind the patient to eat. Multiple peer-reviewed studies have shown that the colour red and blue can support eating habit of person with dementia. The use of coloured crockery for people with dementia may support their perceptual difficulties; the importance of the colour is that it is in contrast to the food and table. In addition to contrasting coloured crockery, good lighting in dining rooms or during the dining room experience is essential. The ambience of the dining room experience should be quiet, relaxed and not overly crowded. Mealtimes should be unhurried and free from distractions, as people with dementia may be easily distracted by noise and over stimulation. The dining room environment could be enhanced with relaxing music, which may reduce agitation. The dining environment where possible should include tables where residents/patients may eat together and for optimal social interaction tables for people are recommended.

Effective interventions include flexible meal times, providing food high in energy, modified diets based on needs and wishes of the individual patient, supplements between meals, bite-sized foods that are easy to pick up, small portions and regular diet, offering one food item at a time, and dietary supplements. Keep in mind a person's

past history with food and be flexible with food preferences. In addition to a healthy diet, insufficient physical activity may lead to loss of appetite. Aspiration can also lead to feeding difficulties. Aspiration occurs particularly with thin liquids. Soft and pudding-like consistency can be tolerated better. Make sure dentures fit and visit the dentist regularly. As the disease progresses, loss of appetite and weight loss may become concerns. In such cases, consult a doctor if the person with dementia experiences significant weight loss (King & King, 2016; Sarikaya et al., 2017).

Personal Care and Hygiene

It is quite common for to help a person with dementia manage their hygiene. As the disease progresses, their ability to use items such as combs and toothbrushes may also decrease. They may forget what these items are and what they are used for. Memory loss can affect a person's ability to remember how to do tasks, as well as whether to do them. They may lose interest in, personal grooming. They may neglect basic activities such as bathing and changing their clothes.

As a person's dementia progresses, they will need more help with everyday activities such as dressing, washing, and toileting. Some practical and simple solutions can be developed to help the patient's dressing problems. When helping a person with dementia, choose comfortable clothing rather than items with buttons, zips and fasteners. Having a wash can be very complex tasks because of the many steps involved. Routines help with bathing to make washing, bathing and showering safer and easier (Alzheimer Derneği, 2020).

Toileting and dementia

Another problem in Alzheimer's patients is incontinence of the bladder and bowels particularly in the middle and late stages. The first and most important step is to determine the possible causes. If the cause is not medical and treatable, some practical and simple solutions can be developed. For example you can limit the fluid intake before bedtime. You can consider using padded undergarments or adult briefs (Alzheimer Derneği, 2020).

Explaining Dementia to Children and Young People

When a close family member or friend develops dementia, it is likely that every member of the family will be trying to cope with their own feelings. Offering clear explanations and plenty of reassurance that people can live well with dementia can help children and young people to adjust and manage their feelings. They may need encouragement to ask questions. Listen to what they say so you can understand what is worrying them. It is very important to encourage your children to go on their lives.

Find activities children and teens can do with a person with dementia. But don't give them too much responsibility and don't let these responsibility take up too much of their time. Let the child or young person know that, if it's possible, simply being with the person with dementia and showing them love and affection is one of the most important things they can do. Try to make sure that the time they spend with the person is pleasurable. Activities could include going for a walk together, playing games, sorting objects, listening to music or making a scrapbook of past events. Take photographs of the child or young person together with the person with dementia, to remind you all that there can be good times. Make sure that the child or young person knows that you appreciate their help. Show them how they are helping the person with dementia (Alzheimer Vakfı, 2020).

Driving and Dementia

For people in the early stages of Alzheimer's, people can still drive. However, over time, dementia affects the skills needed for safe driving. The condition is important both for the person's safety and the safety of others. Most drivers with Alzheimer's disease will need to stop driving .

Signs of unsafe driving;

- Driving too slowly,
- Making errors at intersections,
- Making slow or poor decisions in traffic,
- Forgetting how to locate familiar places,
- Failing to observe traffic signs.

When to stop driving;

Most drivers with Alzheimer's disease will need to stop driving in the moderate stage of dementia. Some types of dementia have certain early symptoms that mean an end to driving might be sooner. Some people with dementia retire from driving with their own will when their memory is not so bad and they are aware of the stages of the disease.

If your loved one shows signs of unsafe driving including getting lost when driving to familiar places, confusing the brake and gas pedals, failing to observe traffic signs, driving too slowly, making slow or poor decisions, hitting the curb while driving, driving at an inappropriate speed, getting annoyed easily and frequently when driving, it's time to stop driving.

If you are confused about the topic ask yourself these following questions: Do I feel safe while the person living with dementia is driving? Would I feel safe if my child was in the car the person with dementia driving? If your answer to these two questions is 'absolutely no', ask your loved one to stop driving as soon as possible.

Giving up driving is not always an easy decision for a person with dementia loving driving. Suggest ways for the person to manage their daily life without driving. Arrange for family members and friends to provide transportation. Use delivery services and have their favorite food delivered right to their door. Have the barber or hairstylist come to the person's home. If the person still insists on, the doctor can write, "Do not drive" on a prescription pad, and you can show this to the person. If the person living with dementia is unwilling to give up driving, consider these last-resort preventive strategies: Control key access. Keep keys out of sight. If the person with dementia wants to keep a set of keys, offer keys that won't start the vehicle. Disable the vehicle. Remove a battery cable to prevent the car from starting, or ask a mechanic to install a "kill switch" that must be engaged before the car will start. Sell the vehicle. If you can make do without the vehicle, consider selling it. Discontinuing driving should not cause social isolation. The person living with dementia should be kept active with other activities (Philipp-Metzen & Schönhof, 2017).

7.3 Ethical Dilemmas of Caring

Individuals with dementia, family members, professionals, caregivers, impact of caring on society bring many ethical dilemmas and ethical violations. Each person has their own identity and so it is important to always maintain their dignity and self-esteem (Balci, 2019).

Progression of dementia will vary from person to person and each will experience dementia in a different way. That's why 'One size fits all' does not work when it comes to providing care and support people with dementia. When evaluating ethical issues, it is advised that prejudice and discrimination against people be considered

Communication barriers that get in the way of ethical behavior;

- Speaking for a person with dementia without letting him/her speak up for himself/herself,
- A threatening, despising, judging or blaming way of talking, patronising them,
- Not allowing them to process the information and work out their response,
- Making assumptions, and believe we are right about the assumptions,
- Avoiding being honest and truthful as honesty often appears to conflict with,
- Thinking or assuming others know what you are thinking and feeling (Karataş, 2016).

Because Alzheimer's and other types of dementia affect the ability of the brain to make decisions and remember information, they often present various ethical dilemmas to family members and caregivers. During the moderate and severe stages of AD, patients may lose the capacity to determine and express what they want. To maximally respect patient autonomy when they become incompetent, it is now common practice to ask these patients during the earlier stages of AD what they want done and/or who will make decisions for them when they are no longer able make these decisions themselves.

Problems that occur in the moderate and severe stages of AD primarily involve conflicts between the values of respecting patient autonomy maximally and paternalistically trying to protect them. These problems include whether the AD patient's caregivers should try to influence the patient in ways they don't disclose to get him or her to do what they want, whether they should withhold information because it may be highly upsetting to the patient, and, especially during the later stages of AD, whether caregivers should outright lie to the patient to avoid causing psychological stress (Howe, 2006).

Informing and Explaining Dementia Diagnosis

Some research found that many people with dementia are not told of their dementia diagnosis. Physicians may be concerned about the person's reaction and, not wanting to trigger emotional distress in their patient, they may just skip over discussing the diagnosis or may prefer to discuss the process only with their family. While the desire to avoid upsetting the patient and their family is understandable, it is important for health professionals to use ethical principles. In dementia, the early stages offer the chance to take care of legal and financial issues for the future and discuss medical preferences with family.

Driving Decisions

For many, driving is a sure sign of independence. Families and caregivers may have concerns about a person's ability to drive, when and how to reduce or stop driving, and preserving his or her independence. But, if you hesitate too long and your loved one ends up hurting someone because they made a poor choice as they drove. Some situations where the person is not safe to drive turn into a very distressing decision for both the person and their family. You may ignore the person with dementia and his/her feelings about driving. You may use patronizing and oppressive speech toward the person with dementia.

Safety in the Home

Your loved one may demand to continue to live independently at home, but it is a common ethical dilemma whether they are still safe to do so. There are several precautions you can take to improve safety at home, and you can also bring in others to help at home, too. Moving into residential or nursing care and when to move dementia patient to nursing home are among the many ethical challenges in the care of person living with dementia.

Enacting the Power of Attorney

Autonomy involves the right to make our own decisions. As dementia progresses, this ability fades and it becomes time to consider enacting (or activating) the power of attorney. Designating someone to act on your behalf and who should be involved in decision-making are among the many ethical challenges in the care of person living with dementia. Making a power of attorney for a person with dementia could be different between countries.

Consent for Treatment and Clinical Trials

In the early stages of dementia, your family member can probably understand the risks and benefits of a treatment. But, as their memory and executive functioning decline, this ability blurs. Make sure they really do understand these issues before signing a permission form.

Hiding Medications in Food

In the middle stages of dementia, it's possible that dementia may cause the person to be resistant to taking medications. Some caregivers have tried to eliminate this battle by disguising pills and hiding them in food. Others argue that it is ethically inappropriate because it's "tricking" the person into taking the medicine.

Sexual Activity

The question of when someone is able to consent to sexual activity when they have dementia poses a great challenge. But, this question of consent in dementia remains for many. Merely a diagnosis of dementia does not prevent someone from being able to consent, and many argue that sexual activity is a highly important factor for maintaining quality of life. The challenge comes in knowing how to protect the right to engage in meaningful sexual activity but prevent someone from being taking advantage of by another.

Therapeutic Lying

Is lying to your loved one okay when the truth would be distressing to them? Generally, it's best to use other techniques like distraction through a subject change or a meaningful activity, or attempt validation therapy. For example, if someone is asking where their mother is (and she passed away many years ago), validation therapy would suggest that you ask this person to tell you more about their mother or ask them what they loved about her.

Genetic Testing for Apolipoprotein E (APOE) Gene

Genetic testing can prompt many ethical questions. These include to whom the results will be disclosed, what the next steps should be if you do carry the APOE gene, and how to cope with this information. The results do not

necessarily indicate if the person will develop dementia; they simply indicate the presence of the gene which poses an increased risk. Because there are so many ethical considerations about genetic testing, and the results do not directly link to outcome, the Alzheimer's Association does not recommend genetic testing for the APOE gene on a regular basis at this time.

Blood Tests that Predict the Development of Alzheimer's

There are blood tests being developed and researched that have been reported to be potentially very accurate in predicting years in advance who will or won't develop dementia. Similar to the APOE gene testing, these tests pose questions about what to do with that information.

Administering Antipsychotic Medications

Antipsychotic medications can effectively treat psychosis, paranoia, and hallucinations, thus reducing the person's emotional distress and potential for self-harm. However, they also pose an increased risk of negative side effects. The use of antipsychotics should never be the first option when determining how to better respond to, and reduce, the challenging behaviors in dementia. Some families have concerns about experiencing unexpected and severe side effects.

Stopping Dementia Medications

Dementia medications are prescribed with the hope of slowing down the progression of the disease. Effectiveness varies, The question of how much this type of medicine helps and when it should be stopped is difficult to answer. The issues on starting a new medication, changing their medication, discontinuing some medications are challenging because no one knows if the person with dementia might be far worse off without the medicine, or not. It is important to seek medical help from professional healthcare providers.

End of Life Decisions

As persons with dementia near the end of their life, there are several decisions their loved ones need to make. Some have been very clear about their preferences long before they developed dementia, and this can significantly ease the process. Others, however, have not indicated what they do or don't want in terms of medical treatment, and this leaves the decision-makers guessing what they think the person would want. End of life decisions include options like full-code (do CPR and place on ventilator) vs. Do Not Resuscitate, feeding tube wishes, and IVs for hydration or for antibiotics (Heerema, 2021; RLP., 1999). It would be better to use checklist for reflecting on ethical dilemmas and ethically challenging situations (prince, 2015).

7.4 Legal aspects / resources

Alzheimer's disease is a progressive brain disease that causes cognitive impairments. As the illness progresses, the person with dementia gradually loses their ability to communicate and being able to make good decisions. Many people are unprepared to deal with the legal and financial consequences of a serious illness such as Alzheimer's disease. It is important for families to designate legal and financial planning arrangements following the diagnosis of dementia.

Persons with dementia are undergone forensic psychiatric examination more frequently to determine if a power of attorney is needed or not, whether the patient is capable of making their own decisions about their care and other issues, judicial determination of capacity.

Alzheimer's disease typically progresses slowly in three general stages: early, middle and late (sometimes referred to as mild, moderate and severe in a medical context). Each has its own specific signs and symptoms (Alzheimer's Association, 2019).

Mild cognitive impairment (MCI) is an early stage of memory loss, Individuals maintain the ability to independently perform most activities of daily living. Even if there are social changes in dementia, these changes aren't severe enough to significantly interfere with daily life. The ability to judge and maintain personal care is still intact. At first, a person may need only prompting or a little help. Taking measures to improve safety becomes vital as a part of labor and social security law. Families need different types of plans including when to stop driving, financial planning and planning for next steps. Legal and medical experts say that many forms of planning can help the person and his or her family address current issues and plan for next steps.

Moderate cognitive impairment; There are some impairments in cognitive abilities and behavioral changes (speaking, judgement and executive dysfunctions) that are strong enough for you to notice. Your loved one is unable to live independently and supervision will be required. There are increased difficulty in legal and financial issues.

Severe cognitive impairment; All cognitive functions are affected by dementia in severe cases. Behavioural problems and disorders are common. The symptoms progress to the point that it becomes difficult to live alone or take care of oneself. People with dementia and their families need supports and services on legal matters as well as other services in community .

Legal issues of people living with dementia, the circumstances under which the person may be held liable for the acts, unlawful act and defaults are complex process. The joint roadmap to be created by the person with dementia, lawyers, family members, social workers and professionals is important for the process management. Social and legal rights of people with dementia vary from country to country. However, the rights of individuals with dementia are protected by both national and international laws.

A lasting power of attorney is giving a designated person the authority to make health care decisions on behalf of the person with dementia to ensure that the person's health care and financial decisions are carried out. As Alzheimer's disease affects the person mentally, people living with dementia can not distinguish a good from a bad act.

[Legal, financial, and health care planning](#)

Families beginning the legal planning process should discuss their approach, what they want to happen, and which legal documents they'll need.

- Health care wishes of someone who can no longer make health care decisions,
- Financial management and estate plan wishes of someone who can no longer make financial decisions,
- Responsibilities of health care insurance for people with Alzheimer's or other dementias.

Social Security Guide

There are some general benefits and opportunities provided by the social security systems to help people those who have needs because of a disability which could be due to dementia. Although social security program systems vary from country to country, there are some basic guidelines for the social security programs.

- If the individual with dementia works, is insured through an employer or pension policy, etc., it is necessary to read all policies regarding chronic/progressive diseases and make sure what the plan covers and what is not. In cases where the language or terminology is not sure, it is necessary to contact the experts or official institutions,
- If the person with dementia is 65 or over, the opportunities and supports provided by the state for the elderly should be checked,
- Individuals with dementia can benefit from the social security rights provided to the disabled,
- When the individual with dementia is no longer able to work, a specialist or social security institution should be contacted for the conditions of private disability insurance.

Advance Health Care Directives for People with Dementia

A durable power of attorney for health care designates a person, sometimes called an agent or proxy, to make health care decisions when the person with dementia can no longer do so.

Advance Directives for Financial and Estate Management

Medical and legal experts say that the newly diagnosed person with Alzheimer's or a related dementia and his or her family should create or update a will as soon as possible after diagnosis.

Advance Planning Advice for People with Dementia

- Start discussions early. People in the early stages of the disease may be able to understand the issues, but they may also be defensive, frustrated, and/or emotionally unable to deal with difficult questions. The person may even be in denial or not ready to face their diagnosis. This is normal. Be patient and seek outside help from a lawyer or geriatric care manager if needed. Remember that not all people are diagnosed at an early stage,
- Gather important papers. When an emergency arises or when the person with dementia can no longer manage their own affairs, family members or a proxy will need access to important papers, such as a living will or financial documents. To make sure the wishes of the person with dementia are followed, put important papers in a secure place and provide copies to family members or another trusted person. A lawyer can keep a set of the papers as well,
- Review plans over time. Changes in personal situations — such as a divorce, relocation, or death in the family — and in state laws can affect how legal documents are prepared and maintained. Review plans regularly, and update documents as needed,
- Reduce anxiety about funeral and burial arrangements. Advance planning for the funeral and burial can provide a sense of peace and reduce anxiety for both the person with dementia as well as his or her family,

- Private medical insurance. Read health insurance policies on chronic disease/ progressive disorders and diseases. Check if the health insurance covers or consider what it covers in detail. If you are unsure about the language or terminology, contact the personnel department or your financial planner,
- A disability benefit. If you're living with dementia, you may be entitled to a disability benefit. You should contact official organisations to claim the benefits to be provided by the state, you should contact official organizations,
- Watch for signs of money problems — Problems managing money may be one of the first noticeable signs of dementia. To provide support, while also respecting the person's independence, a family member or trusted friend can help,
- Establish consent to manage finances — As the disease progresses, a family member or trustee can take additional steps. Consider being named as a legal proxy to access and manage the person's financial affairs to prevent serious problems,
- Protect against scams or fraud .Different types of scam: Telephone, email, or in-person scams can take many forms, such as; identity fraud and identity theft, fraudulent get rich quick schemes, phony offers of prizes or home or auto repairs, insurance fraud, health scams such as ads for unproven memory aids, threats (Alzheimer's Association, 2019; National Institute on Aging, 2000; Yücel, 2020).

8 Unit 7: Caring for the Caregiver

8.1 Emotions & Thoughts through the Journey

Millions of people around the world are family caregivers of People with some type of dementia, and caring means meeting the needs of the Person in different activities of daily living (such as support in hygiene, feeding, dressing), as well as in instrumental activities of daily living (such as financial management, planning and making purchases, home maintenance, among others), in an approach that should always seek to be person-centered (McGillick & Murphy-White, 2016).

If, in the early stages of dementia, the care provided is based on mutual cooperation and shared responsibility between the caregiver and the Person with dementia, in the more advanced stages, and due to the changes and progressive difficulties inherent in the evolution of the disease, this cooperation becomes more “unbalanced” and demanding for caregivers. An increasingly active role is assumed in the management of different tasks, responsibilities and challenges increase and there is greater involvement in decision-making. However, it is important to note that, throughout this process, this “journey, the Person with Dementia should continue to play an active role, to be heard and to have their identity and dignity respected.

From a holistic point of view, caring for a Person with Dementia is demanding and involved in numerous challenges, whether physical, emotional, psychological or social (Mace & Rabins, 2006), and therefore, we easily understand that it is a complex and multidimensional process. This is due to the Caregiver's need to, on the one hand, ensure that they respect the dignity, life history, personality and identity of the Person with Dementia, and promote their comfort, well-being and positive perception of quality of life (McGillick & Murphy-White, 2016), but on the other hand, not dismissing their own feelings and emotions underlying the caregiving process, as well as their own physical and psychological health.

The literature and the reports of several caregivers refer that caring for someone with dementia can be, on the one hand, a rewarding process from which positive emotions and feelings emerge, but on the other hand, it can be something exhausting, where high levels of stress are present and that could represent a great burden for the caregiver. We know that, due to the slow and insidious progression of most dementias, the average duration of care may vary between 4 and 10 years after diagnosis - In other words, caring is a long-term process. However, no disease process is the same and everything varies from Person to Person, from diagnosis to diagnosis. This uncertainty about the future may also have a major impact on the caregiver's mental health, due to the doubts it causes, the persistence of care and the overload that may result.

In this sense, and resulting from the act of caring, great changes and adaptations may occur that are conditioned by the needs of both, such as: moving house to be closer to the Person with Dementia, changing the lifestyle, roles and daily routines. Taking care of someone requires, in the first instance, realizing that there may be changes in the relationship between both, and that over time, we will be faced with a decrease in the Person's autonomy. These new caregiver responsibilities require time, energy and psychological resources, as well as a feeling of “heaviness” associated with responsibilities and uncertainty about the course of the disease (Hoover & Sano, 2019). Caring for someone, regardless of age group, often involves adapting working hours, which can also lead to more challenges at work and, consequently, increased stress, early retirement, and absence from work (McGillick & Murphy-White, 2016).

As mentioned earlier, and according to Rowe and other authors (Rowe et al., 2016), the role of the family caregiver ends up having an impact on the physical, psychological and financial well-being of other family members. Family caregivers may have, in addition to high levels of stress and overload, anxious and/or depressive symptoms, a perception of decreased social support, a negative impact on the immune system and even on cognitive function, as well as sleep difficulties.

Because of all that caring for someone involves, it is so important that the Caregiver takes care of himself, as well as the Person he is supporting. Very often, we realize that Caregivers are focused only on the needs of their family member, and end up neglecting or ignoring their own needs, which can be an added challenge when we talk about taking care of themselves properly. According to the Alzheimer's Society (2022), taking care of yourself is extremely important to stay physically, psychologically and emotionally healthy, so that the relationship and the way you provide care is carried out in the best possible way for both of you. It is essential to be well, to provide good care.

In this way, it becomes imperative that the caregiver is able to assume self-care routines. By itself, this self-care can also represent an additional requirement, since it is common for the time available for this to be reduced and for the concentration of responsibilities and care for the Person with Dementia to occupy a large part of the time. Each caregiver will experience caring for others in their own way. There may be days when you feel like you're coping well and other days when you feel like you can't do it anymore. There may be parts of care that you manage and consider more accessible, others that you will find more difficult, and sometimes this perception can change from day to day, depending on the caregiver's emotional and psychological state, and this constitutes another challenge. It is normal for you to experience a range of very different emotional reactions, sometimes even extreme ones, as the dementia progresses, it causes the Person with Dementia's abilities and personality to change, and it is understandable that the nature of their relationship with the Person also changes over time (Dementia Australia, 2019).

For this reason, and considering the most common emotional and psychological reactions in caregivers, these can in fact have a great impact on their well-being and on the perception of quality of life. In this sense, it is important for you to know that the following feelings, emotions or reactions are common and "normal" to occur (Alzheimer's Society, 2019; Mace & Rabins, 2006):

- Sadness and a feeling of hopelessness, whether associated with the entire care routine, or with the progression of dementia, as well as the change in roles and family dynamics,
- Rage and anger at the onset of the disease and associated symptoms, as well as the perception of lack of help from others,
- Embarrassment and shame associated with behavioral symptoms of the Person with Dementia that are often not understood by family members, friends, close people, or by society, since stigma and misinformation still prevail,
- Fear about the future because, although there are signs and symptoms common to the various dementias, the path associated with the diagnosis varies from person to person and according to the type of dementia,
- Fear of failing or of not providing the best care to the Person with Dementia, in which the feeling of guilt is often associated with them - for example, if there was something they could have done to prevent the

disease from progressing, if there is any type of adjunctive therapy, if the way I take care of my family member is the one that makes them feel better,

- Longing associated with who the Person was before the diagnosis of dementia, the independence and autonomy they had, the way they related and communicated. Nostalgia is also part of the grieving process that is inherent to the onset of dementia, which brings with it losses of associated abilities,
- Loss of interest in people or activities, since the caregivers' focus is usually on the Person with Dementia, and they often end up forgetting about themselves, their interests and their well-being,
- Feelings of loneliness, which can be associated with reduced time spent with significant others, or with the fact that caregivers sometimes choose to leave their jobs or hobbies they previously had,
- Mood changes that are also related to the existing overload, to the behavioral symptoms of the person with dementia, to fatigue and to the physical and psychological tiredness that may exist.

Caring for someone can also impact not only the mental health, but also the physical health of the caregiver, as the following situations/conditions are frequent (Mace & Rabins, 2006):

- Lack of attention to diet and appetite changes,
- Vitamin deficits,
- Disregard of physical symptoms (e.g. gastrointestinal disturbances, sleep disturbances, pain);
- Memory changes and,
- Increase in cortisol levels, which are very much associated with high levels of stress, and with an impact on the immune system.

However, caring for someone can also bring about positive feelings and emotions, including (Alzheimer's Society, 2019):

- Learn new skills and abilities, or improve existing ones,
- Caring for a person who has cared for you in the past,
- Strengthen family relationships and with the Person with Dementia,
- Feel proud of the journey and the work you are doing,
- Support someone who is important to you and,
- Look for new ways to continue to share good times and have positive experiences with the Person with Dementia.

According to (Rowe et al., 2016), when caregivers integrate and accept the experience of caring as something positive, feelings and sharing arise such as gratitude, strengthening of relational ties with the Person with Dementia and other family members, and the feeling of belonging. Duty accomplished. There are also other caregivers who share that they feel valued, useful and that this experience has provided them with personal growth.

8.2 Self-Care strategies

Just as dementia affects each Person differently, the experience of caring will also vary and be influenced by the caregiver's life history, values, beliefs and the relationship that existed before diagnosis. In some moments, or in certain periods of time, the positive feelings may prevail, and in others, the negative ones. It is a "journey" with ups and downs, in which it is important to be attentive to the other, but also to yourself. Thus, and based on emotional and psychological reactions, as well as the impact that care can have on the caregiver's mental and

physical health, it is essential that you take time for yourself. This can be another challenge at this stage you are experiencing, however, we share some guidelines that may help, such as (Alzheimer's Society, 2019; Dementia Australia, 2019):

- It is important to recognize what you feel and how you feel, trying to manage your feelings and emotions. Being aware of what you feel is an important step to make it easier to deal with this process, and can help you make decisions about what is right for you and the person you care for,
- Be realistic and kind to yourself. Everything you do is a lot and requires effort. Everyone who cares for a person with dementia will need help at some point. Focus on what you can do and try to accept that you may need help with some things, trying not to compare yourself with yourself or the situation of other caregivers,
- Set priorities. Many times you have to do a lot of things at once, which can be difficult to manage and can contribute to you feeling exhausted, both physically and psychologically. Reflect on the tasks that will really have to be taken on by you, and those that can be delegated to someone, regardless of whether they occupy a short space of time in your day-to-day,
- Taking care of yourself means taking care of your mental and physical health, being aware of warning signs and symptoms that may be present - not only those that were already present and that may have worsened, but also new symptoms. Going to the doctor regularly is essential. Staying physically healthy is an important part of maintaining your mental health, so taking care of your diet, getting regular exercise and getting enough sleep is crucial at this stage,
- Find ways to rest, to take regular breaks, whether on small walks (alone or with a partner), or to get away from care and ask someone to take care of them for an hour, a day or a week. It can be a challenge as it requires creativity and organization, but it is possible to do. It should be noted that it is common for People with Dementia, when they are in a new environment and with new people, to find it unsettling and unsafe, so it is important to plan this break in advance so that it can be a positive rest experience,
- Remember the positives aspects. While you will have to deal with different changes, adaptations and challenges, try to focus on some of the positive things about caring for and supporting the Person with Dementia,
- Try something new, for example, watching a show, enjoying dinner, watching the sunset, taking an online course on a topic you really enjoy,
- Seek help! You are not alone. There are qualified professionals who can help you, both in terms of care related to activities of daily living (such as bathing, dressing, eating, etc...) and psychologically. There are also support groups made up of other caregivers who can be of help. Caregiver support groups provide the opportunity to exchange information and benefit from the experience and knowledge of others in a similar situation (Hoover & Sano, 2019). When we realize that there are other People who not only understand what we feel, but also experience situations very similar to ours, we have the opportunity to receive and offer emotional support, free from judgments or misunderstandings, and this will help the problem gain a different dimension. Sometimes smaller or more relativized, thus contributing to increase well-being and reduce the feeling of overload,
- Seek legal and financial support, as caring for a Person with Dementia can affect their legal and financial situation in many ways – there are caregivers who are forced to stop working, for example. Look for information about existing support and benefits and/or ways to make working hours more flexible.

8.3 Grief and preparation for “after-care”

Following what we discussed earlier, the trajectory of dementia is something unique, which always depends from person to person. What can happen to a particular person with dementia, may not happen to another, and there is a need to deal with unpredictability, with the unknown, with the constant changes that always require an adaptation process. In the most advanced stages, in which the autonomy of the Person with Dementia in the small tasks of daily living is already greatly reduced, and the Caregiver starts to assume not only the control but also the motor execution of the same, that is, it is already necessary to feed or dress the Person, for example, there is a feeling of anticipated grief, caused by the real and daily perception of these losses.

And because Dementia brings with it other associated health complications, it is important to think, reflect and talk about the post-care moment, in which the person with Dementia they care for will no longer be here, since dementia is a life-limiting disease (Alzheimer’s Society, 2019). For a long time, the caregiver identified himself and assumed this same role. But if this role brought with it many challenges, the reverse will as well. Responses to the death of a family member with dementia are multifaceted (Rowe et al., 2016). In this logic, it is important to understand that grief is a natural process associated with the loss of something or someone, which brings with it different emotional, psychological and physical reactions (Worden, 2018).

The course of a dementia, due to its specificities, presupposes, from the outset, the experience of a series of losses and inherent mourning that are inherent to them, not only for the Person living with Dementia, but also for the informal caregiver who lives close to the disease, the loss of capabilities, changes in the personality and character of the Person, physical losses and the disappearance of previously outlined projects. Therefore, on the one hand, you will be dealing with the death of the Person with Dementia and on the other hand, dealing with the end of your role as a caregiver (Alzheimer’s Society, 2019).

In addition, you may have left your job, the life you knew before the dementia will also have changed and, therefore, leaving your role of caregiver and at the same time dealing with the death of your family member will also be a challenging phase. It is also common to experience manifestations of grief that may seem somewhat contradictory, and as mentioned above, the experience of each Caregiver will naturally be different and individualized. However, generally speaking, the most common reactions, emotions and feelings reported by Caregivers of People with Dementia are as follows (Dementia Australia, 2019).

- Sadness for what could have been or what was lost,
- Shock and pain,
- Disbelief and difficulty accepting the situation,
- Guilt for something from the past or care,
- Relief for both the Person with Dementia and the caregiver,
- Anger and resentment for what happened and,
- Lack of purpose in life now that the caregiver role has ended and difficulty finding meaning in the loss.

These feelings can occur, but how long they last will depend. There are no rules for grieving – we all react to loss in different ways. What is important to emphasize is that all this is a natural process, deeply particular and variable.

After the death of the Person with Dementia it can be important, for example, to re-establish past relationships, take time for yourself and your feelings, seek help if you feel it is necessary, write a journal or even share your experience (Dementia Australia, 2019).

8.4 Services and social support

Taking care of yourself means asking for help at the moment and planning in advance the type of support you may need in the future, so below we share with you the contacts of some associations / entities that may be useful:

<https://www.alzheimer-europe.org/>

<https://www.alzint.org/>

<https://alzheimerportugal.org/>

<https://www.alzheimers.org.uk/>

<https://alzheimer.ie/>

<https://www.spomincica.si/>

<https://www.ceafa.es/es>

<http://www.alzfae.org/>

<https://www.alzheimerdernegi.org.tr/>

If none of these links are related to your country, you can look for the contact at the following address:

<https://www.alzheimer-europe.org/about-us/who-we-are/members>

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