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Alzheimer's Information Book for Patients' Relatives

COSVITEC

TECHNICAL UNIVERSITY

ALZHEIMER'S INFORMATION BOOK FOR PATIENTS' RELATIVES

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ALZHEIMER’S INFORMATION BOOK FOR PATIENTS’ RELATIVES

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The evolution of the letter A

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"Funded by the Erasmus+ Program of the European Union. However, European Commission and Turkish National Agency cannot be held responsible for any use which may be made of the information contained therein".

PREFACE

Alzheimer’s, a type of dementia, increases in parallel with the elderly population in the world. There are 55 million dementia patients in the world today. While the proportion of the elderly in the population increases in almost every country, this number is expected to reach to 78 million in 2030 and 139 million in 2050. Between 60% and 70% of dementia patients have Alzheimer’s. Alzheimer’s is a progressive neurodegenerative disorder progressively reducing the patient’s cognitive function. With the increase in the elderly population, Alzheimer’s patients are also doing so day by day. The increase in the number of Alzheimer’s patients brings with it emotional, social, and economic problems. Especially in underdeveloped and developing countries, Alzheimer’s patients and their relatives faces serious problems. Also, the care of these patients is very difficult. The patient’s relatives meet the majority of the care responsibilities of the patient. One of the main problems of caregivers and patient relatives, who have many emotional, social, and economic problems due to the burden of caring for Alzheimer’s patients, which is one of the diseases with the highest care burden among patients, is that they do not know how to deal with these problems. Another problem is the lack of care places. The inadequacy of day care houses which are important necessity in every city increases the difficulties of patient relatives. It brings a significant care burden to the relatives of the patients. This book was written to be useful to caregivers and their relatives who give care for people with dementia and Alzheimer’s. It is considered that this book will provide important support to the relatives and caregivers of the patients. The book provides information to the relatives of the patients regarding what the disease is, how patients can cope with their emotional and behavioural problems, how to communicate with patients, their personal care, nutritional problems, how to deal with urgent problems, how to provide home and street security, what they can do for mental and physical empowerment, in which institutions they can get support, and their legal rights. Also, there is a section in this book on how to cope with the emotional and social problems they experience due to the heavy burden of care for their loved ones.

This book is a part of the “Erasmus+ KA2 Adult Education project called REMEM, supported by the European Union and the Turkish National Agency”, under the coordination of Pamukkale University. The book is published in Turkish and English. The book is free and available to everyone. The book will be published both on paper and electronically. It is considered that the book will reach many relatives and caregivers of Alzheimer’s patients.

Prof. Dr. Şahin KAPIKIRAN
Denizli, 2022

REMEM PROJECT

You are reading Alzheimer's Information Book for Relatives book which is one of the outputs of "Click me, if you forgot / REMEM" Project as numbered 2019-1-TR01-KA204-074782 supported by Turkish National Agency under Erasmus+ Key Action 2 Strategic Partnership in the field of Adult Education (KA204).

In REMEM Project, Pamukkale University as coordinator and beneficiary institution, Kırklareli University and Denizli Innovation Association from Turkiye, Cosvitec from Italy, and Cluj-Napoca University from Romania have taken part.

Alzheimer's disease affects more and more people around the world. Especially in Western Europe, it is reported by the researchers that Alzheimer's and dementia diseases are the most common diseases compared to the whole world. Individuals who live in a home with Alzheimer's patients experience many problems and uncertainty about the patient's burden of care and how patients should be treated. More than 40% of persons who are responsible for patient care report that their emotional stress is high or too high. For these reasons, depression, intense stress, and strain are the most common negativity that can be seen in the relatives of patients. The patient relatives' information book will help to reduce these negativities. Both the figures put forward by the World Health Organization and the strategic objectives of the European Union reveal the importance of taking urgent and effective measures and developing strategies in this regard.

For this purpose, a book has been prepared in electronic versions, in both Turkish and English. The electronic versions of the books are available on the https://remem.eu/ *project website.*

With the happiness of completing our book;

We would like to thank to the Presidency of Turkiye's National Agency for support of our project.

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Assoc. Prof. Arzum IŞITAN
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CHAPTER 1

WHAT IS ALZHEIMER'S?

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Chapter Content

1.1. What is dementia?

Dementia is defined as a pathological process in the brain. The diagnosis of dementia - Alzheimer's disease or a related condition is made to a patient when there are signs of weakened memory, impaired thinking and behavioral disorders. The first signs noticed by the family may be difficulties in remembering recent events or carrying out simple, well-known activities. Patients may also experience mental confusion, changes in personality or behavior, impaired judgment, difficulty finding their own words, inconsistent ideas, and impaired orientation. Dementia of vascular origin is just as common.

1.2. What is Alzheimer's disease?

It's been over 110 years since we first discovered Alzheimer's disease. While we've made a lot of progress in our understanding of this neurodegenerative disease, we're still waiting and hoping for a cure. Alzheimer's disease is the most well-known form of dementia, which gradually causes significant memory loss and affects mental function. Some time ago, this was also called senile dementia. In addition, there is vascular dementia, Lewy body dementia, front temporal dementia. The disease generally begins to manifest after the age of 65, but there are also cases in which it appears from the age of 40-50 [1].

Alzheimer's disease is the most common cause of dementia [2]. Dementia of vascular origin is just as common; this disease occurs when the blood supply to small brain regions is insufficient and causes the destruction of cells in those regions.

Alzheimer's disease affects the brain regions that control thinking, memory, and language. It begins progressively and the patient's condition generally degrades slowly. At the moment, the cause of the disease is unknown and there is not always effective treatment. These abnormalities are characteristic of Alzheimer's disease. This disease is found in all social classes, it is not related to sex, ethnicity or geographical location.

1.2.1 What causes Alzheimer's disease?

The causes of Alzheimer's disease have not yet been discovered by scientists. All that is known is that it occurs as a result of brain damage. Although we do not yet know the exact cause, there are some important factors, such as heart disease, age, headaches or genetics. Spotted heart attacks can be caused by high blood pressure that can rupture blood vessels or blood clots that obliterate the vessels, with insufficient blood output.

The genetic factor plays an important role: about 5-15% of cases are hereditary. Several specific genetic abnormalities may be involved. Some of these can be inherited when only one parent has the abnormal gene. That is, the abnormal gene is dominant. An affected parent has a 50% chance of passing the abnormal gene to each child. About half of these children develop Alzheimer's disease before the age of 65. A genetic alteration affects apolipoprotein E (apo E), a protein component of some lipoproteins that carry cholesterol into the circulation. However, genetic testing for apo E does not reveal whether a specific person will develop Alzheimer's disease. Therefore, such investigation is not routinely recommended.

1.2.2. What are the symptoms of Alzheimer's?

Alzheimer's is a disease that gradually makes its presence felt, but over time the symptoms worsen and make their mark on the safety of the elderly. They can become a danger both to themselves and to the people around them.

Alzheimer's disease symptoms:

- Orientation and coordination issues;
- Concentration problems;
- Communication problems;
- Organizational problems;
- Memory loss;
- Depression;
- Lack of energy.

1.3.2. What are the symptoms of Alzheimer's disease?

The manifestations of Alzheimer's disease vary from patient to patient. Its effect depends on the person's condition before the onset of the disease, his personality, his physical condition and his previous way of life. To describe the symptoms of Alzheimer's disease, it is best to proceed through a classification by stages: the initial stage, the stage of average evolution and the evolved stage. As already mentioned, not all patients have the same symptoms; are variable from one patient to another.

The classification of Alzheimer's disease in stages allows the entourage to assess the progression of the disease, the consequences of possible problems in a timely manner and to plan in time the necessary measures to meet future needs.

Loss of autonomy it is very important that early and timely diagnosis involves a global approach, both from a medical perspective and from the perspective of the person with dementia and their family. It has been shown that there are people who do not want to be evaluated or, if they are, do not want to know the result, which has been interpreted as a resistance to medical intervention for some, an attempt to maintain control and resist the stigma associated with such an evaluation, rather than denying the disease.

The entourage and the caregivers must also know the stages, the patients being able to present short phases of lucidity.

I. The initial stage

The initial stage is often ignored and unjustly interpreted by specialists, family and friends as senility or as a phenomenon of normal aging. As the onset of the disease progressively sets in, it is difficult to accurately determine the onset of the disease.

The person can:

- It’s hard for him/her to talk;
- The presence of obvious memory disorders, especially the memory of recent facts / events;
- Difficult orientation over time;
- Get lost in familiar places;
- Failing to make decisions;
- To lose all initiatives or motivations;
- Show signs of depression or aggression;
- To lose interest in fun or ordinary daily activities.

Early detection is key to more effective treatment for Alzheimer’s disease and other forms of cognitive impairment, and new research shows that using test it is possible to detect cognitive abnormalities associated with these diseases.

II. The stage of average evolution

As the disease progresses, the disorders become more obvious. The patient with Alzheimer’s disease has difficulties in daily activities and may:

- Present serious memory disorders, especially when it comes to remembering recent facts and names;
- He became unable to live alone without difficulty;

- He became unable to do his housework and his usual travels;
- You become very addicted;
- Presents hallucinations and delusional ideas.

III. The evolved stage

This stage is characterized by a dependence and a total inactivity of the patient. Memory disorders are severe and mental degradation caused by the disease becomes visible.

The patient can:

- She/he had trouble feeding.
- Cannot recognize loved ones, friends or personal items
- He had difficulty understanding and interpreting events
- She/He can't find himself.
- He had difficulty moving
- May have urinary and fecal incontinence
- May be behaving inappropriately in public
- You become forced to use a wheelchair or stay in bed.

1.3. Stages of Alzheimer's Disease

These are 7 stages in Alzheimer's Disease:

Stage 1: Normal

Stage 2: Very Mild Changes

Stage 3: Mild Decline

Stage 4: Moderate Decline

Stage 5: Moderately Severe Decline

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Stage 1: Normal

In the first initial phase, we will not be able to observe any symptoms that the patient exhibits. The solution at this stage would ***be a scan or an imaging test*** that shows how the brain works and the detection of the first signals that reveal if they have Alzheimer's. In each of the six stages of the disease's evolution, relatives or caregivers will see more and more changes in their thinking and reasoning. At this stage, Alzheimer's disease is not detectable and no memory problems or other symptoms of dementia are evident [3].

Stage 2: Small Changes That Are Hardly Noticeable

The loved one's behavior shows some small differences in behavior that even the doctor cannot notice. The first specific signs of this stage of manifestation for loved ones may be forgetting one or more words or objects being placed in the wrong places. The senior may notice minor memory problems or lose things around the house, although not to the point where the memory loss can be easily distinguished from normal age-related memory loss [4]. The person will still do ***well on memory tests*** and the disease is unlikely to be detected by loved ones or doctors. At this stage, the subtle symptoms of Alzheimer's disease do not interfere with the patient's ability to work or live independently. But we must pay attention to how we make the difference between the signs and symptoms of Alzheimer's disease, and the small age-specific changes that are a normal phenomenon of aging.

Stage 3: Slight Decline

It is the stage characterized by ***changes in the thinking and reasoning of the loved one***, such as the phenomena of:

- Forgetting what he read;
- Not remembering the names of new people, she/he meet;
- Repetition of same questions;
- Disorganization fails to make plans or organize.

At this stage, the family members and friends of the senior may notice cognitive problems. Performance on memory tests is affected and physicians will be able to detect impaired cognitive function. People in stage 3 will have difficulty in many areas including [5]:

- Finding the right word during conversations
- Organizing and planning
- Remembering names of new acquaintances

- People with stage three Alzheimer's may also frequently lose personal possessions, including valuables.

Stage 4: Moderate Decline

During this period, the problems in ***thinking and reasoning that notice in stage 3 get more obvious, and new issues appear***. The patient might:

- Forget details about themselves;
- Have trouble putting the right date and amount on a check;
- Forget what month or season it is;
- Have trouble cooking meals or even ordering from a menu.
- In stage four of Alzheimer's, clear-cut symptoms of the disease are apparent. People with stage four of Alzheimer's:
- Have difficulty with simple arithmetic
- Have poor short-term memory (may not recall what they ate for breakfast, for example)
- Inability to manage finance and pay bills
- May forget details about their life histories.

We can help with everyday chores and their safety. We have to be sure that they aren't driving anymore and that someone isn't trying to take advantage of them financially.

Stage 5: Moderately Severe Decline

During the fifth stage of Alzheimer's, ***patients begin to need help with many day-to-day activities.*** People in stage five of the disease may experience [6]:

- Significant confusion
- Inability to recall simple details about themselves such as their own phone number
- Difficulty dressing appropriately

On the other hand, patients in stage five maintain a modicum of functionality. They typically can still bathe and toilet independently. They also usually still know their family members and some detail about their personal histories, especially their childhood and youth [6].

Stage 6: Severe Decline

Patients with the sixth stage of Alzheimer's disease ***need constant supervision and frequently require professional care*** [7]**.** Symptoms include [8,9]:

- Confusion or unawareness of environment and surroundings;
- Major personality changes and potential behavior problems;
- The need for assistance with activities of daily living such as toileting and bathing;
- Inability to recognize faces except closest friends and relatives;
- Inability to remember most details of personal history;
- Loss of bowel and bladder control;
- Wandering.

Stages 7: Very Severe Decline

Stage seven is the final stage of Alzheimer's disease. Because Alzheimer's disease is a terminal illness, ***patients in stage seven are nearing death***. In stage seven of the disease, patients lose ability to respond to their environment or communicate [10]. While they may still be able to utter words and phrases, they have no insight into their condition and need assistance with all activities of daily living. In the final stages of the illness, patients may lose their ability to swallow [10].

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8. Stages-Brain Matters Research. Available online at: https://brainmattersresearch.com/stages/
9. The Seven Stages of Alzheimer' Disease. Available online at: https://www.seniorsbluebook.com/articles/the-seven-stages-of-alzheimers-disease

THE OTHER INTERNET RESOURCES:

Https://www.alztennessee.org/help/caregiver-support/caregiver-resource-library/stages-of-alzheimers-disease

https://www.webmd.com/alzheimers/guide/alzheimers-disease-stages

https://www.udaipurblog.com/forum-purple-run-for-alzheimers-awareness.html

https://alzheimerprepa7.wordpress.com/2017/02/05/stages//

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https://webspace.science.uu.nl/~ooste108/ExpC/website1/v2/7stagesofalzheimers.htm

https://npseniorliving.com/the-seven-stages-of-alzheimers-disease/

CHAPTER 2

DIAGNOSIS AND TREATMENT OF ALZHEIMER’S

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Chapter Content

2.1. Introduction

There are 100 billion nerve cells (neurons) in the brain. Each nerve cell connects with the others to form communication networks. Nerve cell groups have specific tasks. Some are related to thinking, learning, and remembering. Others help us seeing, hearing, and smelling.

Brain cells work like tiny factories to do their job. They feed, generate energy, build equipment, and get rid of waste. Cells also process and store information and communicate with other cells. Keeping everything running requires coordination as well as large amounts of fuel and oxygen.

Scientists point out that Alzheimer's prevents some parts of a cell factory from functioning well, and it is not known where the problem starts. Like a real factory, backups and failures in one system cause problems in other areas. As the damage spreads, cells lose their ability to do their job, causing irreversible changes in the brain and eventually dying [1,2].

2.2. What is the Difference Between Alzheimer's and Typical Age-Related Changes?

The differences between Alzheimer's and typical age-related changes are simply explained in the Table2.1. Not all forgetfulness should be perceived as dementia, and not all dementias as Alzheimer's [3]. However, it would be correct to make a diagnosis as a result of a good physician examination and tests.

Table 2.1. Differences between Alzheimer's and typical age-related changes [3]

Alzheimer's and Dementia Symptoms	Typical Age-Related Changes
Poor judgment and decision making	Making a bad decision once in a while
Inability to manage the budget	Lack of monthly payments
Losing track of history or season	Forgetting what day it is and remembering later
Difficulty in speaking	Sometimes forgetting which word to use
Misplacing things and not being able to undo the steps to find them	Losing something from time to time

2.3. Diagnosis of Alzheimer's

The only definitive way to diagnose Alzheimer's is not easy. However, your doctor can diagnose it using other exams and tests to assess mental abilities, diagnose dementia, and rule out other conditions.

There is no single diagnostic test that can determine whether a person has Alzheimer's. Physicians (usually with the help of specialists such as neurologists, neuropsychologists, geriatricians, and geriatric psychiatrists) use a variety of approaches and tools to aid in diagnosis. While they can almost always determine whether a person has dementia, it can be difficult to determine the exact cause.

Your physician will likely run several tests to determine the diagnosis. They may be mental, physical, neurological, and imaging tests.

Your doctor may start with a mental status test. It can be helpful in assessing their short-term memory, long-term memory, and place and time orientation. For example, they may ask the patient questions to remember what day is today, who is the head of state, or a short list of words.

Then, he or she will likely do a physical examination. For example, they may check her/his blood pressure, evaluate her/his heart rate, and take her/his temperature. In some cases, they may collect urine or blood samples for testing in the lab.

Your doctor may also perform a neurological exam to rule out other possible diagnoses, such as an infection or an acute medical problem such as a stroke. During that examination, they check patient's reflexes, muscle tone, and speech.

Your doctor may also request brain imaging studies. These studies that will create images of brain may include [1,4]:

- *Magnetic resonance imaging (MRI):* MRIs can help detect important markers such as inflammation, bleeding, and structural problems.
- *Computed tomography (CT) scan*: CT scans take X-ray images that can help your doctor look for abnormal features in the brain.
- *Positron emission tomography (PET) scan:* PET scan images can help your doctor detect plaque buildup. Plaque is a protein substance related to symptoms of Alzheimer's.

Other tests your physician may do may include blood tests to check for genes that show patient has a higher risk of Alzheimer's.

2.4. Alzheimer's Treatment

Alzheimer's does not yet have a cure, but treatments for the symptoms are available and studies are ongoing. Although the current Alzheimer's treatments cannot prevent disease progression, they can slow the worsening of dementia symptoms and improve quality of life for Alzheimer's patients and their caregivers. Today, there is a worldwide effort to find ways to treat the disease, delay the onset of the disease, and prevent its development.

For early and moderate Alzheimer's, your physician may prescribe medications containing some active ingredients. These drugs include the types that can help with memory.

Your physician may also prescribe medications to reduce some of the emotional and behavioral problems (such as depression, restlessness, aggression, instability, hallucinations) that accompany Alzheimer's symptoms [5].

2.5. Other Treatments and Therapies of Alzheimer's

In addition to the prescription drugs known today to delay memory lapses, many people with dementia, including Alzheimer's, use herbal remedies, dietary supplements, or other alternative therapies to help treat the disease's progression and symptoms. Diet, physical activity, and mental activities can help slow the progression of the disease.

2.5.1. Nutrition

It has been demonstrated that a healthy diet can reduce the risk of Alzheimer's and help slowing the progression of the disease. Specifically, it is thought that eating fish and leafy green vegetables (such as spinach, kale, and lettuce) and cruciferous vegetables (such as broccoli and cauliflower) has a positive effect.

A colorful diet can also be important. Especially dark-colored fruits and vegetables often contain chemicals called antioxidants that help protecting cells from damage. Other foods that have been studied for possible brain-protective effects include turmeric, a yellow spice used to make some curries, and soy protein.

Ginkgo Biloba; the most mentioned herbal ingredient in the treatment of dementia symptoms is ginkgo biloba, an extract taken from the leaves of the ginkgo tree. The extract is rich in antioxidants and is widely used to improve a wide variety of bodily functions, from circulation to mental function. There are not many studies proving the benefit of ginkgo biloba for people with dementia, but overall it appears to have very few side effects and requires taking it with a physician's advice. These can prevent or delay the onset of dementia, help with memory problems, and even help slow the progression of the disease.

Other supplements used by individuals with dementia provide complementary nutrition such as Vitamin E, Selegiline, Melatonin, DHA (an omega 3 fatty acid found in fish).

Like ginkgo biloba, vitamin E and selegiline are rich in antioxidants. For a long time, low levels of vitamin E have been associated with the development of dementia. However, it's unclear how its use as a supplement might affect dementia once it's diagnosed. The hormone melatonin, which is normally secreted by our own body, is considered to help people with other problems related to the sleep-wake cycle, such as insomnia and sunset.

Many herbal and over-the-counter supplements are not as carefully monitored or regulated as prescription drugs, so ask your physician whether a supplement should be used. Also, some dietary supplements should not be taken with prescription drugs, as they have the potential for serious interactions. As a result, such herbal supplements should be taken under the supervision of a physician [6].

2.5.2. Physical Activity and Exercise

Physical activity and exercise maintain the health of the brain, resulting in less mental decline with age. Even calming activities such as walking, and gardening have been shown to have health benefits. The studies conducted demonstrate that physical activity and exercise help slowing the progression of dementia.

2.5.3. Brain Exercise

Studies has shown that mental exercises such as puzzles and brain training games can help slowing the progression of cognitive problems such as memory loss and decrease in thinking skills. Popular brain exercises include Sudoku, crossword puzzles, and Lumosity (a website that offers cognitive games). Other brain exercises that may be helpful include playing board games or card games and reading books.

2.5.4. Integrative and Holistic Medicine Treatments and Therapies

Integrative and Holistic Medicine is a broader approach and treatment understanding that considers the individuality of each patient as essential, such as acupuncture, ozone therapy, homoeopathy, aromatherapy, phytotherapy, which were previously outside the scope of medicine. In recent years, more and more physicians are using traditional treatment approaches and methods alongside drug treatment.

Other therapies, such as art, music therapy, or aromatherapy, can help people with dementia remembering and experiencing memories more fully through the use of familiar colors, sounds, and smells.

Bright light therapy demonstrates some hope in helping with the restlessness and sleep problems often associated with dementia. In this type of therapy, the person sits next to a light therapy box that emits light that mimics natural light. This type of treatment is considered to help resetting the internal clock and helping a person with dementia sleep better at night [7].

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CHAPTER 3

WHAT IS THE PATIENT'S MENTAL STATUS AND HOW TO DEAL WITH IT

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Chapter Content

3.1. Introduction

Symptoms of Alzheimer's and other associated dementias are typically memory-related, but mood and behavioral changes occur as mental information processing worsens.

It can be devastating if a person's lifestyle, daily routine, and social life are interrupted and permanently changed by cognitive decline. Loss of communication skills, access to memories, and reduced overall functioning result in a variety of emotions such as anger, frustration, and anxiety. Dementia also causes suspicion since situations become difficult to understand. The disease reduces a person's barriers to expressing their emotions, causing resentments, outbursts of anger, and even excessive laughter [1].

3.2. Dealing with Emotional Problems Related to Dementia

In order to deal with emotional problems, first, understanding the reasons behind emotional and behavioral problems is an important step in helping your loved ones and gaining their cooperation.

Dementia is associated with a range of emotional problems. Problems can arise not only from the direct effects of the disease on the brain, but also from indirect sources such as changes in living conditions, routine, and social relationships. Common emotional problems experienced by people with dementia and their caregivers include (but are not limited to) [2]:

- Anger and Disappointment
- Depression
- Anxiety

3.2.1. Anger and Disappointment

Anger often arises as a response to feeling scared, frustrated, embarrassed, or humiliated. What appears to be random aggression could be the result of something in the environment. For example, visiting new places full of strangers can be frightening and overwhelming for people with dementia. In the same way, being surrounded by activity and noise can be distracting or upsetting. Some people with dementia may become angry or frustrated when a caregiver tries to help them as they cannot successfully complete a task on their own.

The first step in dealing with anger in Alzheimer's and dementia patients is to understand where their anger originates. While angry or aggressive behavior can sometimes appear spontaneously in people suffering from mental or memory disorders, it can generally be caused by one underlying cause or multiple causes. A better understanding of the triggers and causes of your loved one's anger will help you preventing aggressive behavior and making it easier to calm angry situations [1,3].

In people with Alzheimer's and dementia, anger may be related to:

1-Physical Triggers

The person may be angry because of discomfort, pain, dizziness, nausea, or exhaustion, or they may feel frustrated by the inability to perform simple physical tasks.

2-Emotional Triggers

The person may become angry due to over-stimulation or boredom. Feelings of being overwhelmed, lonely, or bored can all trigger anger or aggression.

3-Mental Triggers

Mental confusion is one of the leading causes of anger and aggression in Alzheimer's and dementia patients. It can be triggered by a sudden change in environment, such as lost thought chains, mixed memories, or a shift from one caregiver to another [4].

What can we do?

- Caregivers should try to break up complex tasks into smaller manageable steps to avoid making their loved one with dementia overwhelmed or frustrating. Focus on performing each step before giving further instructions that may be difficult to remember.
- If you can identify the cause of their distress, check if it's possible to mitigate or fix the problem.
- Avoid physical contact and NEVER react to violence by force unless your personal safety or the safety of someone else is threatened. Trying to gain physical control of the dementia patient often increases their anger and aggression.
- Use a calm tone of voice and avoid outward displays of distress, sadness, anger, or fear. These signs are often spotted by the angry person and will likely make their own distress and tension worse.
- Always be courteous and reassuring. Do not try to argue or reason with the person. Instead, be sympathetic and accept their anger and disappointment.

- Remember that people suffering from Alzheimer's, dementia, and other memory disorders should not be punished for their anger or aggressive behavior. It is one of the most common mistakes made by loved ones and untrained caregivers. Do not forget: The person you love is suffering from an ailment that they cannot control. Moreover, they are unlikely to understand why they are punished or condemned. In fact, many patients forget their outbursts immediately or soon after they happen.
- If possible, remove yourself from the room or environment. Give yourself and the person time to calm down. It makes it easier for you to react and can calm or quell their anger.

Finally, if all else fails, give your loved one a chance to calm down [1,3,4].

3.2.2. Depression

Depression is very common in Alzheimer's patients, especially in the early and middle stages. Treatment is available and can make a significant difference in quality of life.

Depression is common in people with dementia. The feeling of social isolation and loss of control that comes with the progression of dementia can contribute to depression and loneliness. It can sometimes be difficult for caregivers to distinguish depression from dementia since some of the symptoms are the same, such as apathy (distraction), inability to focus, memory loss, or trouble sleeping. Monitor the signs of depression from dementia. Depression includes mood swings, delusions, restlessness, and anxiety. Other symptoms often associated with depression, such as guilt, suicidal thoughts, and low self-esteem, are not as common [1,3,4].

Depression symptoms

Specialists estimate that up to 40 percent of people with Alzheimer's disease show significant symptoms of depression.

Defining depression in someone with Alzheimer's can be difficult, for dementia can cause some of the same symptoms. Examples of symptoms common to both depression and dementia include [1,3,5,6]:

- Apathy,
- Loss of interest in activities and hobbies
- Social withdrawal,
- Isolation,

- Difficulty in focusing,
- Distorted thinking,
- Also, the cognitive impairment experienced by Alzheimer's patients often makes it difficult for them to express sadness, hopelessness, guilt, and other feelings associated with depression.

Depression in Alzheimer's is not always similar to depression in people without Alzheimer's. Some of the ways depression can be different in someone with Alzheimer's include:

- It may be less severe.
- It may not last long and symptoms may come and go.
- The person with Alzheimer's may be less likely to talk about or attempt suicide.

As a caregiver, if you see signs of depression, discuss them with the person's primary physician. It may be helpful to consult a geriatric psychiatrist who specializes in recognizing and treating depression in older adults because of the complexities involved in diagnosing depression in a person with Alzheimer's.

What can we do?

The most common treatment for depression in Alzheimer's involves a combination of medication, counseling, and a gradual reconnection to activities and people that bring happiness. Simply telling the person with Alzheimer's to "cheer up," "let go," or "try harder" rarely helps. Depressed people with Alzheimer's or without Alzheimer's may rarely or even recover themselves without much support, reassurance, and professional help.

Non-drug approaches

- Support groups can be very helpful, especially for Alzheimer's patients, with an early-stage group who are aware of their diagnosis and prefer to take an active role in seeking help or helping others, counseling is also an option, especially for those who are not comfortable with groups.
- Having a bath.
- Make a list of activities, people, or places the person enjoys and schedule them more often.
- Help the person exercise regularly, especially in the morning.
- Understand the person's frustration or sadness as you continue to express hope that they will feel better soon.

- Celebrate small successes and events.
- Find ways in which the person can contribute to family life and be sure to acknowledge their contribution.
- Reassure that the person is loved, respected, and appreciated as part of the family, not just for what they can do right now.
- Nourish the person with their favourite foods or activities that are soothing or inspiring
- Reassure the person that he/she will not be abandoned
- Various types of antidepressants are available to treat depression. Use the drugs recommended by your physician in the appropriate dose.

3.2.3. Anxiety and Restlessness (Emotional Distress)

A person with Alzheimer's may feel anxious or excited. He/she may become restless and upset when focusing on certain details. Anxiety may stem from difficulty processing both new and old information and experiences. New places and faces can be disturbing for persons with dementia, especially as memories of familiar places and faces fade. Some people respond to anxiety by experiencing insomnia or restlessness, and others may choose to hold on to familiar objects or individuals. Anxiety and restlessness can also be caused by a few different medical conditions, drug interactions, or any condition that worsens a person's ability to think. The person with dementia biologically lives with the loss of the ability to discuss new knowledge and stimuli [7].

Situations that can cause discomfort include:

- Moving to a new place or nursing home
- Changes in the environment, such as travel, hospitalization, or hospitality
- Caregiver changes
- Incorrectly detected threats
- Fear and fatigue from trying to make sense of a confusing world.

In order to prevent or reduce restlessness

Especially if the symptoms appear suddenly, anyone experiencing behavioral symptoms should undergo a thorough medical examination. Treatment depends on a careful diagnosis, identifying possible causes, and the types of behaviors the person is experiencing. With appropriate treatment and intervention, the symptoms of restlessness can be reduced:

- Create a calm environment. Eliminate stressors. It may involve taking the person to a safer or quieter place and offering rest or privacy. Try things that have already been tried and limit the use of caffeine.
- Avoid environmental triggers. Noise, glare, and background distractions (like having the TV on) can be triggers.
- Monitor personal comfort. Check pain, hunger, thirst, constipation, full bladder, fatigue, infection, and skin irritation. Make sure the room is at a comfortable temperature. Be sensitive to fears, misperceived threats, and disappointments when expressing what you want.
- Simplify tasks and routines.
- Engage in activities such as exercising, going for a walk, gardening, playing music, and dancing.

In order to deal with anxiety

Do:

Stand back and ask permission; use calm, positive expressions; give assurance; speak slowly; add light; ask him to choose between two options; focus on pleasant events; offer simple exercise options and try to limit anxiety-provoking stimuli.

Say:

- Can I help you?
- Do you have time to help me?
- You are safe here.
- Everything is under control.
- Sorry!
- I'm sorry you're upset.
- I know it's hard.
- I'll stay with you until you feel better.

Do:

Involve the person in the activities- Try using art, music, or other activities to engage the person and distract attention from the anxiety.

Change the environment- Reduce noise and distractions or relocate. Find outlets for the person's energy. The person may be looking for something to do. Go for a walk or get in the car.

Get hold of yourself- Do not raise your voice, alarm, or be offended, or corner, restrain, criticize, ignore, or argue with the person. Be careful not to make sudden movements out of the person's field of vision.

Give reassurance - Start by reminding your presence. A simple touch can calm an upset person. However, touching can also trigger feelings for someone who is already aggravated. Try saying something like: "I'm here, I'll help you."

Respond to Emotional Content **-** Recognize and respect emotions, regardless of whether the person with dementia is responding to something serious or unimportant. Try expressing something like: "You seem sorry since you're going to be late."

Refocus Attention **-** Instead of letting your loved one dwell on a difficult or painful topic, try to redirect the conversation. Listen carefully and follow the flow of the conversation. Try saying something like: "It must be very important to you to be there on time. You have always been very considerate of other people.

Use a Positive Physical Approach **-** Appear when approaching from the front. Approaching from behind can cause anxiety for the dementia patient. Be sure to use a positive physical approach there.

Identify the Cause Behind the Distress **-** Being aware of the cause of the distress can help solving the problem and avoiding it in the future.

Show Empathy **-** Reacting negatively only makes the situation worse [8].

See the physician - See your physician to rule out any physical cause or medication-related side effects.

3.3. Dealing with Behavioral Problems Related to Dementia

Behaviors and emotions are different, but often related. Sleeping disorders can cause irritability, and hoarding disorder is a result of anxiety. These emotional and behavioral changes are normal in the progression of dementia and may even be considered pervasive and predictable. These two are interrelated.

Some people with dementia cannot distinguish what is socially or sexually appropriate from what is not. For instance, a person with dementia may try to steal or undress when you have visitors. He/she may also try to seek intimacy more often, sometimes even with complete strangers.

In the later stages of dementia, many people act agitated and aggressively. These behaviors often arise during the shower/bath, in response to over-stimulation in the environment, physical discomfort, changes in routine, and frustration with the inability to communicate or perform a task. When this restlessness occurs repeatedly, medications can help.

Problem behaviors may arise in people with dementia. These are normal and simple strategies can help you cope.

3.3.1. Aggression and Anger

Aggressive behaviors can be verbal or physical. They can occur suddenly for no apparent reason, or they can be the result of a frustrating situation. Although it can be difficult to deal with aggression, it can be helpful to understand that people with Alzheimer’s or dementia don’t act this way on purpose.

Causes

Aggression can be caused by many factors, including physical discomfort, environmental factors, and poor communication. In case that the person with Alzheimer’s exhibits aggressive behavior, think on what might contribute to the behavior change.

Physical discomfort

Can the person report physical pain to you? People with Alzheimer’s or other dementias are more likely to have urinary tract or other infections. Because of the loss of cognitive function, they are unable to explain or identify the cause of physical discomfort and therefore may express it through physical aggression. Is the person tired due to insufficient rest or sleep? Is the person hungry or thirsty? Do medications cause adverse effects? Are adverse effects particularly likely to arise when individuals take more than one medication for various health conditions?

Treating Behavioral Symptoms

Especially if the symptoms appear suddenly, anyone experiencing behavioral symptoms should undergo a thorough medical examination. Treatment depends on a careful diagnosis, identifying possible causes, and the types of behaviors the person is experiencing.

Environmental factors

Is the person over-stimulated by loud noises, an over-active environment, or physical clutter? Being surrounded by large crowds or unfamiliar people even in their own home can be over stimulating for a person with dementia.

Does the person feel lost?

- Most people work better at a certain time of the day; usually mornings are the best. Consider the time of day when making appointments or scheduling events. Choose a time when you know the person is most aware and best able to process new knowledge or the environment. Also;
- It can be caused by poor communication.
- Are your instructions simple and easy to understand?
- Do you ask too many questions or explain too much at once?
- Is the person's tension due to your own stress or irritability?

How to respond?

- Try to identify the immediate cause. Consider what happened the reaction just before that may have triggered the behavior.
- If he/she has pain as the cause of the behavior, eliminate the pain. Pain can trigger aggressive behavior for a person with dementia.
- Focus on feelings, not facts. Consider the person's feelings rather than focusing on specific details. Try finding the emotions behind the words or actions.
- Be positive and reassuring. Speak slowly in a soft tone.
- Limit distracting things. Examine the environment of the person and adapt them to avoid similar situations.
- Try a relaxing activity. Use music, massage, or exercise to help calming the person.
- Shift the focus to another activity. The sudden indicent or activity may have unintentionally provoked an aggressive response. Try something different.
- Take a break. If the person is in a safe environment and if you can, get away and take some time to yourself.
- Ensure safety. Make sure you and the person are safe. If the person is unable to calm down, ask for help from others. Always call local emergency services in case of shortness of breath.

3.3.2. Hallucinations

When someone with Alzheimer's or other dementia hallucinates, they may see, hear, smell, taste, or feel something that does not exist. While some hallucinations can be frightening, others may involve mundane visions of people, situations, or objects from the past.

Alzheimer's and other dementias are not the only causes of hallucinations. Other reasons are:

It can be caused by ***kidney or bladder infections***, dehydration, intense pain, or physical problems such as alcohol or drug abuse, and schizophrenia.

In addition, in case that a person with Alzheimer's begins to hallucinate, it is important to seek ***medical evaluation*** to rule out other possible causes and to determine whether medication is needed. It may also be helpful to check the person's eyesight or hearing.

The initial treatment for the behavioral symptoms of Alzheimer's is drug-free approaches, but if these strategies fail and the symptoms are severe, medication may be appropriate. While antipsychotic medications can be effective in some situations, they are associated with an increased risk of stroke and death in older adults with dementia and should be used with caution. Work with a physician to learn both the risks and benefits of the drug before making a decision.

Coping strategies

Be careful when responding to hallucinations. First, assess the situation and determine whether the hallucination is a problem for the person or for you. Is the hallucination disturbing? Does it lead the person to do something dangerous? Does seeing an unfamiliar face cause the person to be frightened? If so, respond calmly and quickly with reassuring words and a relaxing touch. Do not argue with the person regarding the things he/she sees or hears. If the behavior is not dangerous, there may be no need for an intervention.

- **Give assurance**. Respond calmly and supportively. You may want to reply by saying "*Do not worry. I am here. I will protect you. I'll take care of you*." Gentle caress can turn the person's attention to you and reduce the hallucination.
- **Accept the feelings** behind the hallucination and try to find out what the hallucination means to the individual. You might want to say "*You seem worried*" or "*I know this is scary for you*".

- **Use distractions**. Suggest a walk or move to another room. Frightening hallucinations usually subside in well-lit areas where other people are present. Try to turn the attention of the person to music, conversation, or activities you enjoy together.
- **Answer honestly**. If the person asks you about a hallucination or delusion, be honest. For example, “*Do you see him/her*?” if he/she asks. You may want to respond by saying, “*I know you see something, but I don’t*.” This way, you don’t deny what the person saw or heard, but you avoid an argument.
- **Change the environment.** Check for sounds that could be misinterpreted, such as noise from the TV or air conditioner. Search for lighting that casts shadows, reflections, or distortions on the surfaces of floors, walls, and furniture. Turn on the lights to reduce shadows.
- **Cover mirrors with a cloth or remove them** if the person thinks he/she is looking at a stranger.

Rejection of Help

People with dementia may reject help or only seek help from a specific person. Possible causes include insecurity and confusion. He/she cannot remember his/her surroundings or does not know his/her relatives, and although it is more common in advanced stages, the person’s belief that he/she can do everything causes him/her to refuse help in the early stages.

Recommendations

Sometimes it depends on how the individual is approached. For instance, you might say that the regular caregiver will be back soon and that you are helping until the person returns. If worrying about an upcoming event leads to a lack of cooperation, it can be helpful to give up warning of potentially distressing events, such as going to the physician. You should avoid threatening the person with a more difficult and punishing situation. If the person with dementia is not cooperative to gain a sense of independence or control, find a task. For example: “How about you comb your hair while I finish lacing your shoes?”

3.3.4. Hoarding Disorder

Some people with dementia creates their own special collections or supplies by hoarding food or other items. It is usually harmless and makes the person feel safe and in control. Persons with dementia may hide things like under mattresses, dresser drawers, or jars where they hid earlier in life.

Recommendations

Instead of confronting your loved one and correcting him/her, try to adapt. Only intervene if the behavior is destructive or excessive. Check out the usual "hide" places of your loved ones and check the trash or dirty laundry. Check for spoiled food and unsuitable items. Some caregivers find it helpful to keep cabinets locked when not in regular use to limit the number of new hiding places.

3.3.5. Repeating

People with dementia may say or do things repeatedly. They may repeat a word or question or move back and forth. This behavior may stem from feelings of anxiety or fear, and again creates a sense of familiarity and security. It can also be the result of only remembering certain things or forgetting what has been said before.

Recommendations

Allow loved ones participating in repetitive activities that seem to bring comfort without harm. If they do harm, try diverting your loved one's attention to harmless or beneficial activities. Turn his/her attention to something else without worrying him/her.

3.3.6. Sleeping Problems

Sleeping problems are common for people with dementia. Some people sleep during the day and are awake and restless at night. While some can no longer tell the difference between night and day, others are not as active as they used to be and need less sleep as a result.

Causes of sleeping problems

It's important to try to understand what might be causing the problem – the environment, dementia, or medications? It will help decide which strategies might be helpful. Some families and caregivers find that keeping a diary can help them see the developing behavior pattern and pinpoint the cause of the problem.

Physiological or medical reasons

- The brain damage caused by dementia affects the "biological clock" in the brain that manages our sleep patterns.
- Diseases such as angina, congestive heart failure, diabetes, or ulcers

- Pain caused by distresses like arthritis
- Urinary tract infection that causes the frequent need to urinate
- “Restless legs syndrome” or leg cramps, which may indicate a metabolic problem
- Depression, which causes waking up early in the morning and not being able to sleep again
- Adverse effects of drugs such as diuretics
- Sleep apnea and snoring
- A person may need less sleep as they get older

What to do?

- If you think this may be contributing for the problem, discuss stopping or changing the diuretic medication with the physician.
- Arrange a medical check-up to identify and treat physical symptoms
- If the physician agrees, treat the pain with an analgesic at bedtime.
- Discuss with the physician whether sedatives are contributing for the problem.
- Ask the physician whether an evaluation for depression is necessary.
- Ask the physician related to the possible adverse effects of the medication.
- In some cases, it may be necessary to discuss the appropriateness of using sedatives or sleeping pills with the doctor. Also, it may help in the short term to establish a better sleep cycle, but both types of drugs can have negative effects such as increased confusion.

Environmental reasons

- The bedroom may be too hot or too cold
- Inadequate lighting can cause a person with dementia to become disoriented.
- They may not have found the bathroom.
- Changes in the environment, such as moving to a new home or being hospitalized, can cause disorientation and confusion.

What to do?

- Keep the environment as consistent as possible. Do not change where he/she sleeps.

- Check to see if the person is too hot or too cold when they wake up. Dementia can affect their internal thermostats
- Shadows, glare, or poor lighting can contribute to agitation and hallucinations, so provide adequate lighting
- Not being able to recognize himself/herself in the bedroom mirror or others can cause confusion. If there is a mirror in the room, remove it.
- Night lights can help reduce confusion at night and help them find the bathroom.
- If finding the bathroom is a problem, a nightstand next to the bed can help.
- Ensure that the bed and bedroom are comfortable. Familiar objects can help his/her adaptation
- Try to make sure they get exercise enough. Try going for one or two walks each day.

Other reasons

- Going to bed too early
- Sleeping too much during the day
- Extreme fatigue that causes tension and inability to fall asleep,
- Insufficient exercise so that they do not feel tired,
- Drinking too much caffeine or alcohol
- Restlessness after a sad situation,
- Disturbing dreams.

What to do?

Food and drink

- Reduce caffeine (coffee, cola, tea, chocolate) during the day and eliminate it completely after 5 pm.
- Decrease alcohol and discuss possible interactions between alcohol and medication with the physician.
- If you think the person may be hungry at night, try a light snack just before going to bed or when they first wake up.
- Herbal teas and warm milk may help.

Daily routines

- Try not to do things that will upset you after the noon.
- If the person refuses to lie down, try offering alternatives, such as sleeping on the sofa.

- If the person wanders at night, consider allowing it, but check to see if the house is safe.
- Try doing a back massage before going to bed or while you are awake.
- Try a soft music-playing radio by the bed.
- Gently remind the person that it is night and it's time for sleep [1, 9, 10, 11,12].

3.4. Other Issues

Problems with sleep or late evening agitation are often a stage in dementia that eventually passes. Many people with dementia sleep more in the later stages of the condition.

Sleeping problems are among the most difficult symptoms of dementia. Families and caregivers should be able to get enough sleep themselves. Try to provide regular rest periods and regular breaks for both you and the person with dementia [12].

Swearing

People with Alzheimer's or other related dementia swear or "curse" using abusive language. Swears are typically taboo, but sometimes they can be our most basic forms of expression. When a person with dementia is surprised or disappointed, swear words may come to mind. It can begin to occur a lot with the disease, even if the individual never or rarely swears before the illness, or only does so "behind closed doors". It can be irritating and embarrassing to hear your loved one start swearing more often. However, the simple explanation is basically a lack of impulse control [1, 9, 10].

Recommendations

Keep calm and remind yourself that your loved one didn't act this way on purpose. Diverting the attention of the individual, such as changing the subject or opening a favorite television program, can distract from swearing [1].

Medication problems

The patient's drug use is encouraged to take the drugs himself/herself, given by the physician in the first phase. In this process, the caregiver checks whether the patient takes his/her medication or not. Situations such as the patient forgetting to take medication are those that occur frequently [13]. Therefore, in the first stage, a stimulant is needed for the patient to take their medication. Thus, help can be obtained from an application on the mobile phone when the patient needs to take medication. For example, with the REMEM application, the patients can determine at what time they will take the drug with the help of the alarm application. Moderate and advanced Alzheimer's patients need the help of caregivers for drug use. Therefore, caregivers should meticulously monitor the patient's medication intake. They should pay attention to the dose of medication recommended by the physician. It would be helpful to keep a list of when and in what dose these drugs will be used in relation to be giving medication to the patient. These drugs are those that will help patients to lead a quality life as a result of many studies. So far, no drug has been found that can reverse Alzheimer's disease. However, these drugs used are those that both help the patient to lead a quality life and help the disease progress more slowly. When adverse effects are seen in patients due to taking medication, it is necessary to ***consult the physician*** following the patient [13].

If the patient refuses to take medication

The main reason why patients refuse to use the drug may be the unpleasant taste and smell of the drug. Another reason is that the patient may refuse the drug, thinking that they are poisoning him/her due to his/her skeptical state. Medications can be administered by giving them with a small amount of fruit juice, mixing them with their meals, and mixing them with other favorite foods [14].

3.5. Tips for Dealing with Emotional and Behavioral Issues [1,3,5,6,10,11, 12, 14,15, 16]

- **Monitor personal comfort.** Check pain, hunger, thirst, constipation, full bladder, fatigue, infection, and skin irritation. Maintain a comfortable room temperature.
- **Avoid confrontation or arguing about facts.** For example, if someone expresses a desire to visit a parent who died years ago, do not say that the parent is dead. Instead, say, "*Your mother is a wonderful person. I'd love to see her too*".
- **Direct the person's attention**. Try to be flexible, patient, and supportive by responding to emotion, not behavior.
- **Enter their world.** People with Alzheimer's disease sometimes have delusions. Challenging these delusions can only make them feel threatened and insecure. Instead, you should accept the underlying emotion and perhaps redirect their thoughts.

Assume a patient falsely accuses someone of stealing a wallet. “*You must be feeling very bad about your wallet missing. Let’s go look for it*”. He/she can think and express his/her mother as if she is still alive. “*Tell me about her*” you can say. Sometimes entering this world just means playing games.

- **Create a calm environment.** When someone has Alzheimer’s, a noisy room and even background noise can be distracting, even a TV can be too much. The dazzling light and open space can make the patient feel insecure. Try to create a peaceful environment that can help reduce mood swings caused by over-stimulation. You can turn on calming music to create a relaxing mood and make sure the lighting is nice and soft.
- **Relax the person by using calming** phrases and letting the person know you are there. **Be sensitive** to fears, misperceived threats, and disappointments when expressing what you want.
- **Allow** adequate rest between the stimulating events that triggered his/her behavior.
- **Provide a safety object.** A key chain, a towel, etc. that makes him/her comfortable. For example, say things like this will make you feel comfortable.
- **Approve and respond to their requests.**
- **Direct his/her attention.** If the person becomes frustrated or anxious, see whether you can change the subject by bringing up happy memories, playing a favorite home video or song, or asking about something you know the person loves. Or change the subject to an upcoming appointment or task. Redirecting can be very helpful in ending an explosion, so have ideas and tools ready in case you need them. Redirect the person’s attention by introducing a third person to distract them (eg friend, neighbor, or family member).
- **Be understanding rather than confrontational.** A lot of patience can be required when caring for someone with Alzheimer’s. Disease can make people irritable and argumentative. If your grandma seems offended, don’t take it personally- disease speaks. Instead, accept the disappointment and don’t try to correct him/her if he/she has the wrong facts. For example, if he/she is upset that a relative didn’t come to visit and his/her relative died a few years ago, admit that you know how much he/she cares for that person. The aim is to support and recognize his/her reality and feelings, no matter how out of place they may seem.

- **Maintain their self-respect.** Caregivers are often told to break up and simplify the work of Alzheimer's patients. But if you do too much for the person, you can cause anger and frustration, making them feel more helpless and crippled than they really are. You should also consider safety. You can't let him/her drive just because he/she wants to. Striking the right balance is difficult, helping and maintaining without seeming condescending, especially as one's abilities gradually decline as they change from day to day.
- **Take on a leadership role**. It is one of the key recommendations in Daniel Kuhn's Early Stages of Alzheimer's. Someone needs to start making decisions and taking responsibility for the person with Alzheimer's. Especially if that person is your parent, this change may involve a disturbing and temporary reversal of power. Another tricky balancing act: You have to take responsibility while minimizing people's obstacles and maximizing their strength.
- **Don't keep them waiting.** A shorter attention span can cause even a few minutes of waiting for Alzheimer's patients. They become impatient, agitated, and even aggressive. Sometimes problems related with bathing or eating are the result of waiting for a caregiver to organize, not the activity itself.
- **Avoid over-stimulation.** With the best of intentions, caregivers often want to include their loved ones in family gatherings, especially during the holidays. However, many people with Alzheimer's are particularly sensitive to several sounds at once. A big family event can be overwhelming. You might consider a smaller meeting with one or two people instead. Other strategies include limiting visits to a few hours and taking time for a nap. It is another grace to turn off the TV and turn down the music while people are talking and eating.

Useful tips during a period of restlessness: Back off and ask permission; use calm, positive expressions; give assurance; slow down; use visual or verbal cues; add light; guide between the two options; Limit stimuli by focusing on pleasant events and offering simple exercise options.

- **Keep the person physically active.** People with early disease said vigorous exercise sharpened their thoughts and calmed them emotionally. What's more, Alzheimer's disease and depression often go hand in hand, and numerous studies have shown that exercise heals depression. In a 2003 study published in the Journal of the American Medical Association, researchers of University of Washington demonstrated that exercise, along with behavioral management classes for caregivers for Alzheimer's patients, improved physical health and alleviated depression.

- **Sing a melody.** People with Alzheimer's can often enjoy music even in the later stages of the disease. Studies show that they respond particularly well if you sing to them, are more communicative, less aggressive, and less likely to scream. Singing by caregivers can put them at ease.
- **Don't shout.** The patient's problem may not be due to not hearing. Speak in a calm, even and warm tone.
- **Don't continue chatting with another person as if that** person wasn't there. People with experience caring for Alzheimer's patients say they realize that patients are being treated as if they don't exist, and they resent it.
- **Use common and simple words.** But avoid too many pronouns. One may be confused as to who "she", "woman" and "us" are referring to.
- **Use guiding statements rather than open-ended questions.** "Would you like a cup of coffee?" is better than "What would you like to drink?". However, a simple and inviting statement like "Let's have a cup of coffee" is even better.
- **Make eye contact, touch the person, and be conscious of your body language.** Non-verbal cues become increasingly important as the disease erodes language-focused thinking. Because these cues are so important, talking on the phone is often not a substitute for being there in person.
- **Say things that clearly express positive emotions.** In Talking to Alzheimer's, Claudia J. Strauss recommends some nice things to say when you leave after a visit: *"I really enjoyed it", "I always feel good after talking to you"* and "*Seeing you is the best part of my day*" All of these statements send a strong emotional message.
- **Make the most of the last word.** According to Alzheimer's disease specialist Joanne Koenig Coste, patients will likely remember the last word in a phrase often because it is the easiest word to remember. If you ask, "*Would you like to wear a green shirt or a blue shirt?*" only the word "shirt" can remain in the per-

son's mind and you will not get an answer. But Coste says "care partners" (a term that caregivers prefer) can turn this trend into their advantage. Ask "Do you want to wear the green shirt or the blue one?" and the person will say "blue". He/she feels like he/she decided for himself/herself rather than being told what to wear, but the choice has been made so easy that he/she has little to worry about.

- **Find outlets for energy**, such as taking a walk, doing chores, or getting into the car.

Take a break and get support. Alzheimer's can be extremely difficult for both patient and caregiver. You also need to take care of yourself, which will help you better care for the patient. Your health must be a priority. Alzheimer's care is a marathon, not a sprint. Make sure you go out, see your friends, and make time for fun activities. Ask for help when you need it. You can find support groups through local services or the Alzheimer's Association website.

As a result, **caregivers are encouraged to show compassion and connect on an emotional level**, even if the person cannot remember who you are.

Ask for help from someone who has encountered such issues and has resolved the issue. For this, refer to the internet, applications, and books for Alzheimer's patients.

- **Look for the reasons behind every behavior**. Consult a doctor to identify causes related to medications or illness.

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CHAPTER 4

COMMUNICATION WITH ALZHEIMER'S PATIENTS

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Chapter Content

4.1. How Can I Explain the Disease to the Patient?

In clinical practice, there has been a tendency among physicians not to inform their patients about the diagnosis of Alzheimer's. Looking at Medicare data from 2008 to 2010, which includes data for 16,000 people, and interviewing patients receiving Alzheimer's treatment, one study concluded that only 45 percent of physicians told their patients they had Alzheimer's. Physicians had their own reasons not to explain it to their patients: for instance, they believed that telling it would be too traumatic or confusing for some patients.

The attitude may come as a surprise, as we live in a time when the concepts of patient rights and obtaining information are important. However, there are both pros and cons to informing a loved one that they have been diagnosed with Alzheimer's or other types of dementia. Helping relatives of loved ones regarding how to deal with this can be difficult.

Reasons for not informing your relatives about the disease:

First, let's look at why a family member might not be able to provide information regarding a diagnosis of Alzheimer's.

Knowing can trigger a sense of hopelessness. Telling them can cause emotional stress. Not knowing can prevent a person from feeling like a burden on their family. You might think to yourself, "He/she might not notice."

Why tell someone we love has Alzheimer's?

Whatever the diagnosis, they have a right to know. This is the most honest thing to do. Your loved one may suspect that something is wrong. Knowing can bring a sense of relief.

Knowing allows a person with Alzheimer's and their family to draft a plan for long-term care. It allows for advanced care documentation to define family or professional caregivers, or a combination of both, to plan the patient's future life.

Those mentioned are all possible reasons to say or not to say an Alzheimer's diagnosis. If you choose to explain the diagnosis, also consider how you will explain it so you can give your loved ones the support they need.

If you decide to disclose the diagnosis, it is necessary to support loved ones while learning.

People with Alzheimer's or other types of dementia are in such a forgetful stage that they cannot remember or understand what is being said because of this disease. How can we best submit the information and support our loved ones if they are able to understand the diagnosis?

- Include your loved one's physician to explain the options available for medical diagnosis and medical treatment.
- Tailor your description to your loved one's level of understanding.
- Stay positive and support your loved ones by reminding them that you will do everything in your power to support them through that disease.
- Choose the appropriate terminology. An alternative to the labels "Alzheimer's" or "dementia" might be "memory problems." So, say, "There are some things you forgot".
- Be a knowledgeable caregiver. There is plenty of information available through local and national organizations, online, and through books.

As time goes by as an Alzheimer's caregiver, find support for yourself. Consider additional caregivers to complete your team, especially if you're a one-man team. Get support from institutions and organizations that provide professional health services, such as senior service providers and local health centers [1].

4.2. How Can I Contact Him/Her?

Communication is difficult for people with Alzheimer's since they have trouble remembering. They may have trouble finding words or forget what they wanted to say. You may feel impatient and wish they would say what they want, but they can't.

People with Alzheimer's may experience problem to

- find the right word or lose the chain of thought while speaking
- understand what words mean
- pay attention during long conversations
- remember steps in common activities such as cooking, paying bills or getting dressed
- block background sounds from radio, TV or calls
- frustration when unable to communicate

- be very sensitive to touch and tone and volume of sounds.

Also, Alzheimer’s causes some people to become confused related to language. For example, the person may forget or no longer understand English if it is learned as a second language. Instead, he/she can only understand and use the first language learned.

4.3. How Can We Make Communication Easier?

The first step is to understand that the disease causes changes in communication skills. The second step is to try some easy communication tips:

- Make eye contact and summon the person by name.
- Have a warm, loving, and genuine demeanor.
- Pay attention to your tone of voice, how loud your voice is, how you look at the person, and your body language.
- Let him/her make some decisions and get involved.
- Be open to the person’s concerns, even if they are difficult to understand.
- Chat with each other for as long as possible.
- Touch gently.
- If there is a problem while communicating, try to distract the person.
- He can get angry when he/she can’t express himself/herself. Be patient with angry outbursts when someone with Alzheimer’s has trouble finding the right words or putting feelings into words.
- Don’t forget, this is a “speaking” disease, be patient.
- Be as sensitive as possible. Help the person finding words to express their thoughts and feelings whenever they forget or something strange. But be careful not to put words in the person’s mouth too quickly or “fill in the blanks” and don’t correct what they are saying. Try to understand that this is a struggle for the person to communicate.
- Be aware of non-verbal communication. As people lose their ability to speak clearly, they may rely on other ways to communicate their thoughts and feelings. For example, facial expressions can show sadness, anger, or disappointment. Grasping through their underwear may tell you they need to use the bathroom.

When talking effectively with a person with Alzheimer's [2]:

- Offer simple and step-by-step instructions.
- Repeat the instructions and allow more time for the response. Try not to distract.
- Don't talk about the person as if they weren't there.
- Do not talk to the person using "baby talk" or "baby voice".
- Be Direct, Specific, and Positive.
- Say "*let's try it this way*" rather than pointing out errors.
- "*Please do this*" instead of "*don't do this*".
- "*Thanks for your help*" even if the results are not perfect.
- Ask questions that require a yes or no answer. For example, "*Are you tired?*" you can say. Limit the number of options instead of "*how are you feeling*". For example, instead of "*What would you like for dinner?*" you could say "*Would you like a hamburger or chicken for dinner?*".
- Use different words if he/she doesn't understand it the first time. For example, if you ask the person if they're hungry and don't get a response, say, "*Dinner's ready now, let's eat*".
- Try not to say "*Do not you remember?*" or "*I told you*".
- If you are disappointed, give yourself a break.

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CHAPTER 5

EMERGENCIES AND MEDICATION USE PROBLEMS

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5.1. Introduction

Most patients with Alzheimer's have many chronic diseases due to their advanced age. Since the patient is often unaware of his/her own disease, it becomes difficult to understand the disease when the disease does not reach an advanced level. Most patients cannot express their illness. We can understand that he is sick by the uneasiness he experiences. Also, patients may have difficulty expressing their daily needs. In order to understand that he/she has the disease, we need to consider some symptoms. Below are examples of some diseases and symptoms of patients.

5.2. Shortness of Breath

Symptoms

They may show symptoms of rapid and superficial breathing, chest tightness, air hunger, suffocation, bruising on the lips and hands, wheezing during breathing, palpitations, intermittent speech due to shortness of breath, inability to form long sentences, headache, dizziness, and weakness. However, such symptoms can also be those of other diseases. Therefore, it is necessary to see a physician as soon as possible.

What to do urgently

- Opening windows
- Raising the head of the bed
- Humidification of the environment with the humidifier
- The patient should see a physician without delay [1].

5.3. Weakness

If the patient has a long-term weakness, it can be seen as a precursor to a serious illness. However, there is no need to worry for short-term fatigue. If the patient suffers from fatigue for more than 2 days, it may be necessary to see a physician.

What to do?

- Among the things to do for fatigue are walking in the open air,
- Frequent and little feeding
- Eating foods low in sugar
- Feeding with foods rich in vitamin C, as well as dried apricots, dried almonds, hazelnuts, walnuts, raisins, dried figs [2].

5.4. Constipation

Constipation is the name given to three or fewer defecations per week due to slow bowel movements. Constipation, which causes adverse conditions such as defecation difficulty, incomplete emptying of stool, painful defecation, and bloating, is common among intestinal disorders. Constipation can sometimes be seen as an obstructive type and sometimes as a slowdown in bowel movements.

What are the symptoms of constipation?

- Stool that is too hard
- Too little
- Defecating difficulty
- Too rare

What causes constipation?

In the formation of constipation, which is defined as difficulty in defecation, there are factors such as digestive system diseases, unhealthy diet and dietary habits, sedentary life, and drug use. Other answers to the question of what causes constipation can be listed as follows:

- Postponing the need for the toilet
- Eating solid foods
- Stenosis or obstruction in the rectum or colon
- Abnormalities of the nerves around the rectum or colon
- Hormonal diseases
- Dysfunctions of the muscles that play a role in defecation

What foods cause constipation?

It is necessary to avoid consuming certain foods known to cause constipation or to limit these foods as much as possible. Banana, pasta, rice porridge, rice, excessive milk consumption and fast food should be avoided.

If the problem of constipation is still experienced despite careful attention to the diet and active lifestyle, it is necessary to consult a physician for the treatment of constipation.

How is constipation treated?

Wrong eating habits come first among the most important causes of constipation. For this reason, constipation can be prevented by making small changes in the nutrition program first. Precautions can be taken against constipation by avoiding consuming foods that cause constipation and preferring foods that accelerate bowel movements.

What to do?

- Plenty of water and liquid foods should be consumed.
- More action should be taken.
- A diet consisting of fiber-based vegetables, fruits, legumes and grains should be prepared.
- The bites should be swallowed after they have been thoroughly chewed.
- Excessive caffeine consumption should be avoided.
- Excess milk and dairy products should not be consumed.
- Creating a toilet layout and toilet need should not be delayed.
- Consult a physician in cases of persistent constipation.

What foods are good for constipation?

Some of the foods that are good for constipation are:

Dried fruits: Eating dried apricots, figs, damsons and drinking warm water on an empty stomach before breakfast will make the intestines work. These foods are more effective when consumed on an empty stomach in the morning.

Water: If water consumption is not limited for any reason, care should be taken to drink enough water during constipation.

Flaxseed: Flaxseed, which can be consumed by adding it to yogurt, is among the foods that are good for constipation.

White meat: When consuming meat, choosing white meat or fish instead of red meat will relax the intestines (high amounts of red meat cause a straining effect on the intestines).

Foods with fiber: Consumption of foods rich in fiber, such as legumes, beets, leeks, artichokes, spinach, cabbage, cranberries, celery, flax seeds, helps the intestines to act. Beans, peas, and lentils, which are among the fibrous food groups, are good for constipation. All other fibrous fruits except bananas can be consumed.

Olive, olive oil and thyme: Olive is good for constipation when consumed with thyme and olive oil poured on it. It will be beneficial to consume 1 teaspoon of olive oil on an empty stomach, as olive oil facilitates the passage of food from the intestine.

Consuming these foods that are good for constipation for a long time and excessive consumption can cause the intestine to gain immunity and not be able to defecate under normal conditions [3].

5.5. Diarrhea

Diarrhea is bowel movements in which loose and watery stools are passed more often than usual during the day. Diarrhea is short-lived. It usually lasts for a few days and disappears without the need for any treatment. Diarrhea can be acute, that is temporary, or chronic, that is, long-term or permanent.

Acute diarrhea occurs with persistence for one to two days. It can occur as a result of a viral or bacterial infection, or from food poisoning.

Chronic diarrhea refers to diarrhea that continues for at least four weeks. Often there is an underlying medical cause, such as a bowel disease or disorder.

What are the Symptoms of Diarrhea?

Although diarrhea usually resolves on its own, adults who show signs and symptoms of diarrhea that lasts longer than a few days, dehydration, severe abdominal or rectal pain, bloody or black stools, or fever above 39 degrees Celsius, should see a physician. The most important symptoms of diarrhea are;

- Loose and watery stools
- Abdominal cramps
- Stomachache
- Fever
- Blood in stool
- Mucus in stool
- Bloating in the abdomen
- Nausea and a very sudden rush to go to the toilet are also symptoms of diarrhea.

Dehydration is one of the most important symptoms of diarrhea. Dehydration can manifest as extreme thirst, dry skin or mouth, dark urine, little or no urination, weakness, dizziness, or tiredness.

Factors causing diarrhea

Lactose intolerance causes diarrhea. Lactose is a type of sugar found in milk and other dairy products. Some individuals may have trouble digesting lactose and may experience diarrhea after consuming dairy products. Diarrhea may occur in some cases after abdominal or gallbladder removal surgery. Chronic diarrhea may also occur in individuals due to a number of other digestive disorders [4].

How to Prevent Diarrhea?

If there is diarrhea caused by viruses, hands must be washed with soap. Frequent handwashing is required to stay adequately and properly clean. During this 20 second, hands should be continued to be rubbed with soap. If it is not possible to wash hands, alcohol-based hand cleaners and disinfectants containing at least 60 percent alcohol should be used.

Well-cooked and hot foods should be preferred. Raw or undercooked meat and dairy products should be avoided.

Tap water and ice in drinks should be avoided. Drinks such as coffee or tea made with boiling water will likely be safe. However, caffeine and alcohol have the risk of exacerbating diarrhea as well as increasing the need for more water.

5.6. Urinary Incontinence

Urinary incontinence problem, which is more common in women, negatively affects the daily life of the person and reduces the quality of life. The feeling of discomfort caused by the worry of constant wetness, irritation and odor in urinary incontinence can lead to the development of mental problems up to depression. However, this problem can be solved with lifestyle changes and exercises as well as surgical methods.

For a healthy person, the daily frequency of urination should be between 4-6 during the day and 1-2 at night. Therefore, it is not considered normal to urinate more than 7 times a day [5].

What to do?

- Fluid intake should be reduced.
- Fluid intake should be avoided four hours before going to sleep at night, and the bladder should be emptied before going to bed.
- Consumption of juicy fruits and vegetables should be avoided in the evening.
- Excessive consumption of caffeinated, acidic, spicy foods and beverages and excessive alcohol consumption should be avoided.
- Physical activity should be increased, and a balanced and regular diet should be used to support weight loss.
- Smoking habit, if any, should be quitted.

- In order to prevent chronic constipation and difficulty in going to the toilet, fibrous foods should be added to the diet.
- A routine toileting schedule should be established, and, in severe cases, laxative treatments should be applied.
- If the measures we take regarding urinary incontinence and the practices we do for the solution do not work, a physician should be seen.

5.7. Abdominal Pain

Some diseases and stress factors that affect the digestive system can cause chronic abdominal pain.

How is abdominal pain treated? [6]

- It is not possible to eliminate all abdominal pains with the following measures. However, it may be possible to relieve some of the pain.
- Create a healthy diet
- Drink plenty of fluids (but do not overdo it. Water should be taken as needed).
- Try to exercise
- Try to eat little and often
- Do not eat and sleep late
- See a physician if abdominal pain persists for a long time.

5.8. Poisoning

Poisoning can cause illness or death by swallowing, breathing, touching or injecting various drugs, chemicals, poisons or gases. Many substances, such as drugs and carbon monoxide, are toxic only at higher concentrations or dosages. However, ingesting cleaners can be dangerous.

First Aid

How you treat someone who may have been poisoned depends on:

If you do not know the type and amount of the poisoning substance and if you are concerned about poisoning, call the poison control centers of your country.

When to suspect poisoning?

- Burns or redness around the mouth and lips
- Breath that smells like chemicals like gasoline or thinner

- Vomiting
- Difficulty in breathing
- Numbness
- Confusion or other altered mental state
- If you suspect poisoning, be on the lookout for clues such as empty pill bottles or packs, spilled pills, burns on people or nearby objects, stains, and odors.

When to call for help?

Call the emergency number if the person is showing the following symptoms.

- Sleepy or unconscious
- Has trouble breathing or stops breathing
- Uncontrollably restless
- Having a seizure

Call the poison control center if you know you have intentionally or accidentally overdosed on medication or any other substance. **Provide the following information to the center** you call:

Be prepared to describe the person's symptoms, age, weight, other medications he/she is taking, and any information you have about the poison. Try to determine the amount ingested and how long the person has been exposed to it. If possible, have the pill bottle, medicine pack, or other questionable container in hand so you can refer to the label when speaking to the poison control center.

What to do while waiting for help

Do the following until help arrives [7]:

- Swallowed poison. Remove anything left in the person's mouth. If the suspected poison is a household cleaner or other chemical, read the container's label and follow the directions for accidental poisoning.
- Poison on the skin. Remove contaminated clothing using gloves. Rinse skin in the shower or hose for 15 to 20 minutes.
- Poison in the eye. Gently flush eye with cold or lukewarm water for 20 minutes or until help arrives.
- Inhaled poison. Take the person to fresh air as soon as possible.
- If the person vomits, turn his/her head to the side to avoid choking.

- Begin CPR if the person is showing no signs of life, such as moving, breathing, or coughing.
- Ask someone with the ambulance crew to collect pill bottles, packs or labeled containers, and other poison-related information.

5.9. Injury by Falling

Falls are the second leading cause of unintentional injury and death worldwide. Worldwide, an estimated 684,000 people die from falls each year, with over 80% of them in low- and middle-income countries. The group with the highest number of fatal falls are adults over the age of 60.

A fall is defined as an event that results in a person accidentally standing on the ground or other lower level. While all people who fall are at risk of injury, the person's age, gender, and health can affect the type and severity of injury.

Older people are at risk for death or serious injury from a fall, and the risk increases with age. To prevent injury from falling, you can use the Safety PART 6 of this book. In serious injuries as a result of falling, a health institution should be visited as soon as possible [8].

5.10. Pressure Ulcers and Bedsores

What is a pressure ulcer or bedsore?

A pressure ulcer is an area of skin, and sometimes the tissue underneath, that has been damaged by pressure. They are sometimes called bedsores. Ulcers may develop in bony areas close to the skin. An ulcer occurs due to reduced blood flow to the skin and the skin being deprived of oxygen and nutrients.

Causes

Limitation of movement and walking: Sitting or lying in the same position for too long is a common cause of pressure sores. People with dementia may have trouble changing positions without help. This can happen as they move between the bed and chair or reposition themselves while sitting or lying down. Caregivers of them may also sometimes become discouraged or restrict movement since they fear that the person with dementia will fall.

Pressure ulcers also become more likely if the skin thins, dries out, or weakens due to aging or disease: It causes a loss of protective fat and muscle mass and also means the skin may become thinner.

Malnutrition and lack of fluid intake: Not eating and drinking well can weaken the skin and make it unable to heal itself.

Urinary and fecal incontinence: Moisture from leaks can damage the skin.

Poor blood supply: Conditions such as diabetes or vascular disease (for example, in vascular dementia) increase the risk of ulcers.

Restlessness: Clothing often rubs against heels or elbows, damaging the skin and increasing the likelihood of ulcers.

Medications: Some medications can cause a person to be more sleepy or have dry skin.

In general, older people are at higher risk of pressure ulcers, especially if they have difficulty moving. This risk increases even more, especially as dementia progresses.

How are pressure ulcer symptoms detected?

- If a person has red patches anywhere on their skin (especially in areas with pointy bones) and they remain red when lightly pressed with a finger, this may be an early sign of pressure ulcers. Do not ignore these signs.
- The area may also be painful, hard, or hot to the touch.
- Pressure ulcers may be more difficult to detect in people with darker skin. They may appear as patches with a blue or purple tint that does not go away.
- If you help someone with dementia wash or dress, always take a few moments to check their skin, especially the bony areas. Pressure ulcers are most likely to occur on the heels, ankles, knees, hips, spine, elbows, shoulder blades, and back of the head.

If you think you have found a pressure ulcer, contact your GP and seek advice as soon as possible.

Treatment of pressure sores

- The most important part of any pressure sore treatment is removing the cause of the pressure or friction and helping the person move as much as possible.
- If you have noticed a pressure ulcer at a very early stage (called a category-1 ulcer), your GP can usually evaluate the person and advise the district or community nurse.

- The nurse may also talk to you about aids to protect your body (such as pressure-reducing pads, special pillows, covers, or mattresses) and how to hold them. These aids can help preventing pressure ulcers from developing or getting worse. Although they are important, they do not replace the need to move and reposition the person. The nurse can also advise on correct sitting or lying positions (for example, supporting the feet).
- If the skin is cracked, it is called a category-2 pressure ulcer. For category 2 ulcers, treatment usually includes cleaning and dressing the wound. The aim is for the ulcer to heal properly and not become a long-term (chronic) or hospitalization problem. It is important for the person to avoid lying or sitting on the aching area.
- A pressure ulcer of any type can be extremely painful, so regular painkiller may be required.
- Some pressure ulcers, especially chronic ulcers, become infected and even more painful. At worst, this can make the person seriously ill with blood poisoning or a bone infection. It is necessary to take into account the recommendations of the physician for the treatment of an infected ulcer.
- Pressure sores may arise if the patient is in a lying position for a long time. Try to make sure that the person does not stay in one position for more than a few hours. Encourage them to get up during the day and act as independently or with assistance as possible. Consider using a memory aid — for example, a timer alarm — to encourage the person to change their location independently.
- Ask the nurse or ergo therapist to show you how to help the person move or transfer safely between their bed and chair. Lifting aids are available that can help.
- Talk to the nurse about pressure-relieving pads, covers, or mattresses.
- Sitting in a chair or wheelchair can also lead to the development of pressure ulcers and sores. While sitting, encourage the person to change their position in the chair every 15-30 minutes.
- If possible, help them get up and walk at least every few hours.
- Get pressure-reducing seat cushions.
- If there is a condition that causes friction on the person's skin, reduce the friction. As people age, their skin becomes more sensitive. Even a slight rubbing on the skin can increase the risk of pressure ulcers over time.

- If you help the person for moving, be careful not to drag them over the bed or chair.
- Help the person sit in the correct position while in bed. In case that they have to resist sliding down constantly by trying to push themselves back, it will put pressure on the heels and the base of the spine or cause friction.
- Make sure they don’t have rough seams on their clothes or anything in their pockets that could rub against the skin.
- Check whether the bearings are smooth. Wrinkles in the sheets can contribute to pressure ulcers. In case that the person is in the later stages of dementia, they may not be able to easily explain that they are bothered.
- Consider bed linens and clothing made from natural fibers such as cotton or linen. They are less likely to cause pressure ulcers than synthetic materials.

General tips [9]

- Help the person for exercising regularly. Chair-based exercises can help a person stay flexible and also relieve pressure. Exercise also improves circulation. Ask your GP to refer you to a physical therapist for advice on appropriate exercise. For exercises, you can use the Exercise Part 10 of this book.
- Try to make sure the person eats a well-balanced diet that includes plenty of protein (eg, eggs, fish, meat) and fresh fruit and vegetables. They should also drink plenty of fluids. Good nutrition makes the skin healthier and more resistant to ulcers.
- In case that the person has urinary and fecal incontinence problems, be careful not to stay in wet clothes or wet bedding. The risk of ulcers will be greater if the skin comes into contact with urine for any period of time.
- Excessive heat and humidity can contribute to pressure ulcers, so try not to let the person get hot and sweaty.
- Especially avoid tight clothing or tight bedding.
- Make sure the person, especially the skin folds, is completely dry after a bath or wash. Dry them - do not rub.
- Never rub or massage areas where the skin is red, as this can cause further damage.
- If your patient is bedridden, reposition the body to relieve pressure on certain parts of the body. Try to do this approximately every two hours.

5.11. Choking

Choking is the deterioration of tissues as a result of insufficient oxygen reaching the tissues in the body.

What are the causes of choking?

- Backward shift of the tongue as a result of fainting and loss of consciousness,
- Fluid filling in the trachea,
- Foreign body entering the trachea,
- Hanging,
- Damage to the lungs,
- Gas poisoning,
- Drowning (*).

(*) In drowning, a very small amount of water enters the lungs due to the contraction of the trachea during drowning. In cases of drowning, artificial respiration and heart messages should be performed even if 20-30 minutes have passed, especially in cold weather.

In drowning, mouth-to-mouth or mouth-to-nose breathing is possible in water, and this practice should be started while in the water. This application may not be possible in deep waters, so the patient/ injured must be pulled quickly towards shallow water.

In addition to the risk of drowning as a result of jumping into the water, general body trauma or spinal fractures should also be considered. Thus, the head should not be pushed too far back in the water.

What are the general symptoms of drowning?

- Difficulty in breathing,
- Noisy, rapid, and deep breathing
- Sputum collection and foaming in the mouth,
- Bruising on the face, lips, and nails,
- General distress, inaccuracy and indecision in answers,
- Fainting,
- Difficulty breathing, speaking or coughing, a red, raised face are signs of distress. They may point at their throats or grab their necks.

What should be the general first aid procedures in choking? [10]

- The cause of choking is eliminated,
- Consciousness is checked

- ➢ The patient’s vital signs are evaluated,
- ➢ Basic life support is provided,
- ➢ Immediate medical help is sought (*112-999*),
- ➢ Vital signs are monitored.

What should be done?

1. If you think someone is choking, ask them “Are you choking?”. If they can breathe, speak, or cough, they can clear their own throats. If they can’t breathe, cough, or make a sound, they need your help right away.

2. Encourage them to cough and clear the obvious stuffiness in their mouth.

3. Slap. If the cough does not work, you need to give five sharp back blows. In order to do this, help them leaning forward by supporting their upper body with one hand. With the wrists of your other hand, give five sharp back blows between the shoulder blades. After each back blow, check to see if there is anything in their mouth.

4. If the backstrokes do not clear the obstruction, press the abdomen five times. In order to do this, stand behind them and wrap your arms around your waist. Place one hand in a clenched fist between your belly button and the lower part of your chest. Grasp your fist with your other hand and pull sharply in and up up to five times. Recheck their mouths each time.

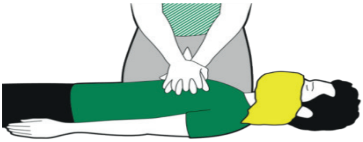
5. If the blockage is not cleared, call the national aid agency (*999 or 112*) immediately for emergency assistance. Repeat five backstrokes and five abdominal thrusts, rechecking his/her mouth each time until help arrives.

How to give CPR to an adult?

It combines chest compressions and rescue breathing to give a person the best chance of survival after cardiac arrest. You need to initiate CPR (cardiopulmonary resuscitation). It means CPR in the literature. In case that an adult is unresponsive and not breathing normally, you should seek emergency help and start CPR immediately.

1. If you find someone who is short of breath, you should do a survey first.

- Do not bring your face close to theirs. In case that you have determined from this that they are unresponsive and not breathing, you should ask an aid to call for emergency assistance as you begin the CRP. Ask an assistant, if available, to find and bring a defibrillator.
- Ask your assistant to put the phone on speaker and hold it towards you so they can maintain a distance of 2m.
- If you are alone, use the phone loudspeaker so that you can start CPR while talking to the ambulance. Do not leave the casualty looking for a defibrillator. The ambulance will bring one.



2. Before beginning CPR, use a towel or piece of clothing and place it over the casualty's mouth and nose. Start CPR. Kneel next to the injured and place the wrist of your hand in the middle of their chest. Place your other hand on the one on your chest. Interlock your fingers making sure they do not touch the ribs. Keep your arms straight and lean over the injured. Press hard to a depth of about 5-6 cm and bring the chest back before releasing the pressure.

Do not give rescue breaths. Keep doing CPR until now:

- Emergency aid arrives and takes over.
- The person begins to show signs of life and begins to breathe normally.
- You are too tired to continue (if it helps, you can switch every 1-2 minutes with minimal interruption in chest compressions).

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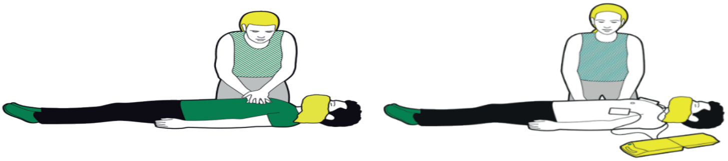

If the victim shows signs of responding, such as coughing, opening his eyes, speaking, and is beginning to breathe normally, place him/her in the recovery position. Monitor response levels and prepare to perform CPR again if needed.

If you used a defibrillator, leave it attached [11].

5.12. Build an Emergency Kit

Emergencies like fires and snowstorms affect everyone's safety, but they can be distressing and confusing, especially for individuals living with Alzheimer's and other dementias. Being prepared is very important. There are steps and measures you can take to be as prepared as possible. However, in case that you find yourself in an emergency and you haven't prepared well in advance, there are actions you can take to keep you and the person living with Alzheimer's as safe as possible:

- Check the weather conditions regularly before leaving the house and adjust the plans as needed. For example, if a storm is expected, consider rescheduling non-urgent appointments.
- Where the person with dementia lives in a residential building or attends an adult day center, learn about disaster and evacuation plans. Find out who is responsible for evacuating everyone in an emergency.
- Make sure the evacuation plan takes into account specific needs. For instance: How will accommodation be provided if a walker or wheelchair is used?
- Provide copies of the person's medical history, a list of medications, physician's information, and family links to people other than the primary caregiver.

What should be in the emergency kit?

Consider packing an emergency kit in a waterproof container and store it in an easily accessible place. Be sure to take into account your needs (e.g. prescriptions, important documents, extra cell phone chargers) as well as the needs of the person with dementia. Use waterproof bags to protect medicines and paperwork and, if possible, keep a backup of important documents in a secure electronic file. Items you may want to include are [12]:

- A few easy-to-change clothes suitable for the weather.
- Medical documents and drug supplies (carry a list of dosed drugs).
- Sneakers.
- A cell phone charger and/or an external power bank.
- A spare pair of glasses if needed.
- Extra identification items such as ID bracelets and clothing tags.
- Copies of legal documents such as power of attorney.
- Copies of Insurance and Social Security Cards.
- Physician's name, address, and mobile phone numbers.
- The last photo of the person living with dementia.
- Hand lotion or other comfort products.
- Bottled water.
- Non-perishable foods, including some liquid meals.
- A favorite item of the person living with dementia (for example, a book, a picture, a bag).
- Record your physician's and Alzheimer's Association phone numbers.

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CHAPTER 6

HOW DO WE DEAL WITH SAFETY ISSUES?

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Chapter Content

6.1. Introduction

Alzheimer’s patients are more likely to experience safety problems in daily life. Alzheimer’s patients experience difficulties in memory loss, distraction, hand-eye dexterity, and healthy use of their body. In this context, they face great dangers at home and on the street. The most important reason for Alzheimer’s patients to encounter these dangers is memory loss. In addition to memory loss, vision loss, and hearing loss can be seen in these patients. Another of the body problems is the loss of eye-hand cooperation in these patients. As a result of these losses, these patients may be exposed to dangers such as burning, cutting, poisoning, domestic fires, falling, electric shock, and gas explosion. Therefore, these patients need to live with a caregiver, including their early stages. Although there is a caregiver, some arrangements are needed in the home to eliminate these dangers. Precautions to be taken for patients to feel safe at home may help them to avoid these dangers to some extent. Especially these patients do not feel safe because of their memory and physical losses. Therefore, it should be considered that he/she may have to relearn everything around him/her. That’s why they have so many worries. They don’t know where to go, what to do, and how to do it. They feel even more insecure when we do not understand what they are feeling and use inappropriate expressions towards them. If safety precautions are taken, an individual with Alzheimer’s can live in the comfort of their own home or a caregiver’s home. As the disease progresses, the person’s abilities will change. However, the home can be adapted to support these changes with a little creativity and flexibility. You can create a home that is both safe for your patient and supports the person’s social interaction and meaningful activity needs with the measures you can create [1,2].

Making necessary changes in the home environment during various stages of the illness can reduce the risk of physical injury. It can reduce the anxiety of both the patient and the caregiver.

Alzheimer’s disease causes a number of changes in the brain and body that can affect safety. Depending on the stage of the disease, it may include [1]:

- **Decision:** forgetting how to use household appliances
- **Sense of time and place:** getting lost in one’s own street
- **Behavior:** easily confused, suspicious or frightened
- **Physical ability:** having trouble with balance
- **Senses:** experiencing changes in vision, hearing, sensitivity to temperatures or depth perception

6.2. Home Safety

What can we do about security?

You need to create a ***<u>Home Safety Checklist</u>*** to ensure your patient is in a safe environment. Below is a list you will create for home security and suggestions for what to do about it:

Evaluate your environment. A person living with dementia may be more prone to safety hazards in certain areas of the home or outdoors. Garages, workrooms, basements, and outdoor areas where tools, chemicals, cleaning supplies, and other potentially hazardous materials are more likely to be found should be considered safe.

Avoid safety hazards in the kitchen. Use devices with auto-off feature. For example, use a tool that will allow an electric tea machine to turn itself off after boiling occurs. When the stove is not in use, we must remove the buttons or turn off the gas. Also avoid using unsafe stoves. Discard poisonous plants and decorative fruits, as they can be mistaken for patient real food. Do not keep vitamins, prescription drugs, sugar-like foods and spices off the kitchen table and counters.

Make sure that the safety devices are operational. Make sure carbon monoxide and smoke detectors and fire extinguishers are available and inspected regularly.

Install the locks out of sight. Place a latch or deadbolt on all doors above or below eye level. Remove locks on interior doors to prevent the person with dementia from locking themselves out.

Light walkways and rooms well. Changes in light levels can be confusing. Create an even level by adding extra lights to the areas between entrances, landings, rooms, stairs, and bathrooms. Use night lights in hallways, bedrooms, and bathrooms.

If you have a gun in the house, consider removing it or keeping it in a locked cabinet. If someone in the household has Alzheimer’s or other dementia, **firearms can pose a significant risk to anyone**. As the disease progresses, the person may not know someone they have known for years and may see him/her as an intruder.

Place medications in a locked drawer or cabinet. In order to make sure medications are taken safely, use a pillbox organizer or keep a daily list and mark each medication as it is taken.

Eliminate tripping hazards. Eliminate discarded rugs, extension cords, and excessive clutter.

Monitor the temperature of water and food. It can be difficult for someone living with dementia to tell the difference between heat

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and cold. Consider installing an automatic thermometer for water temperature or set water heaters to a temperature no higher than 50 degrees.

Evaluate bedroom safety. Do not use electric blankets, heaters, or heating pads to avoid burns or other injuries. If they are to be used, they must be used under your supervision. Provide seating next to the bed to assist with dressing. Make sure cabinet shelves are at an accessible height and items are easily accessible so you can prevent the person from climbing the shelves or objects falling from the top.

Fix large furniture. Make sure bookshelves, cabinets, or large TVs are secured to prevent tipping. Make sure chairs have armrests to provide support when moving from a sitting to a standing position.

Improve laundry room safety. Secure all cleaning products, such as liquid laundry packs and bleach, to prevent potentially harmful chemicals from being swallowed. Consider installing safety locks on washers and dryers to prevent unsuitable items from being placed or removed too soon. Clean the lint filters and drying channels regularly to prevent fires.

Assess the safety hazards in the garage and/or basement. Limit access to large tools such as lawnmowers, grass trimmers. Keep toxic chemicals such as gasoline or thinner out of reach.

Support the person's needs. Try not to create a home that feels too restrictive. The home should encourage independence and social interaction. Open spaces for activities.

Put no keys on top of bathrooms and other rooms. It may cause patients to lock themselves from the inside and then experience great fear as they cannot be opened.

Be prepared for emergencies. Keep a list of emergency phone numbers and addresses for local police and fire departments, hospitals, and poison control hotlines. Eliminate breakable items [1,2,3].

Eliminate breakable items.

Keep backups of necessary things like keys in a safe place [*4*].

Check refrigerators frequently for food spoilage. In the middle and advanced stages of Alzheimer's, they cannot distinguish between fresh and spoiled food. The sense of taste and smell may be decreased due to drugs and illness [2].

In addition to providing safe areas, **it is required to tell them what to do without getting tired.** They should also be told that after providing a safe environment, they have no reason to worry.

Safety measures to prevent falling. Falling is one of the leading injuries in domestic accidents in elderly and Alzheimer's patients. Protect from possible hazards that could cause a fall. For this, take the following measures:

- Carpets and rugs should not have raised ends.
- Carpets and rugs should be fixed to the floor.
- Prevent carpets and rugs from slipping. For this, remove small mat-style objects from all environments of the house.
- Ensure that rooms and halls are well lit.
- Provide high railings to prevent falls from balconies.
- Do not keep cloths that will cause tripping and falling in the bathroom.
- There should be no elevation in the entrance of the rooms of the house.
- Do not have a bathtub in the bathroom. The patient has difficulty in ascending to high places.
- Avoid getting long cables underfoot.
- Prefer beds that are close to the floor to avoid the danger of falling while sleeping.
- Walking around barefoot when the floors are wet can cause you to slip and fall or bump into an object. So, dry the area.
- Install grab bars for showers, tubs, and toilets to provide additional support. Consider installing a shower enclosure.
- In case that there are stairs in the house, ensure that the surface of the stair treads is anti-slip.
- There must be a handrail that will allow it to hold onto the stairs.

Precautions against fire and electric shock and other hazards [3];

In cases where the sockets are exposed or the cables are visible, do not use these sockets and have them repaired. Prevent exposed wires.

- Make sure that natural gas stoves and water heaters are safe.
- In addition to the installations, the use of the products is also very important. Be careful when using electrical products where there is contact with water.
- Use taps marked red for hot and blue for cold to help him/her understand the flow of hot and cold.

6.3. Street Safety

Another important aspect in providing a safe environment for our patients is street safety. Unfortunately, most of our patients may throw themselves into the street with the door open momentarily. Another situation is that the patient in the early stage may go out on the street. In such cases, it is possible for the patient to face great dangers because he/she cannot find his/her way home. Some precautions should be taken to avoid such problems.

Recommendations on going out and preventing disappearance [4,5]:

- Your patients may be likely to walk out of the open door because of boredom or because of hunger, tiredness, and the need to go to the bathroom and the urge to wander aimlessly. Especially if our patient has had the problem of getting lost before, the outer door and windows should be locked.
- Install key-lock deadbolts on doors to the outside of the house or to stairwells
- Use alarms that warn when any door is opened.
- Use a “Stop” or “No Entry” writing or sign with curtains, wallpaper, or paint on doors that open to the outside.
- Do not leave the keys of the outer door on the door so that your patient does not encounter a situation such as going out and locking the door.
- Your patient must have a phone that is easy to use. Have few numbers to call urgently at the touch of a button. These numbers include the caregiver, a close person, doctor, and emergency room numbers.
- Before the disappearance, go to the community police and leave the patient’s fingerprints and information about the persons to be reached in case of disappearance in the fingerprint bank. In case of your patient’s disappearance, the police will initiate the disappearance process without waiting 24 hours.
- Have the patient carry identification or a bracelet with their name, address, and phone number (*4*).
- Some different methods can be developed to ensure that the patient is found in case of loss. One of them is to wear a necklace around the patient’s neck.
- Also, advanced communication technologies can also be used

today. A locator application can also be added to the phone to find out where the patient is from the phone he/she is using. Another method is to attach a monitoring device that can be attached to the patient's favorite belt and watch.

- Alzheimer's patients often want to go out for reasons such as boredom and having nothing to do at home. Going out with the patient may eliminate the patient's desire to go out on his own.
- Apart from this, some activities should be included at home in order to relieve the patient's boredom. They can be done in the physical and mental activities that are mentioned in various parts of the book.
- Have an application to help find location for lost issues.
- Finally, Alzheimer's patients do not like big changes in the home. For this reason, do not make major changes such as changing the place of the furniture in the house or changing the room unless required. One of the frequently heard relatives of the patient points out that they put the patient's belongings in refrigerators or unsuitable cabinets and then show anger reactions when they cannot find these objects. Always put the patient's items such as glasses, phone, wallet and keys necessary for daily use in the same place. Patients often put such items in random places. As a result, they may experience some emotional problems when they cannot find such items. Point out the places where he/she should put his/her things every time without getting tired [5].

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CHAPTER 7

WHAT ARE THE MEMORY PROBLEMS, THE PATIENT EXPERIENCES, AND HOW DO I DEAL WITH IT?

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Chapter Content

7.1. What Should They Do About Daily Life?

Alzheimer's disease is the best-known form of dementia. Although it is common for the disease to start after the age of 65, there are cases where it occurs after the age of 40-50 [1]. In 7 distinct stages, Alzheimer's disease gradually begins to affect the areas of the brain that control thinking, memory, and language, and the patient's condition usually worsens gradually. There is no definitive cure for this neurodegenerative disease.

While current Alzheimer's treatments cannot prevent disease progression, they can slow the worsening of dementia symptoms and improve the quality of life for Alzheimer's patients and their caregivers. Today, there is a huge worldwide effort to find ways to treat the disease, delay the onset of the disease, and prevent its development [2].

Organization of daily living with a patient with Alzheimer's disease usually very difficult. However, there are ways to deal with this situation:

Routine makes life easier: Routine can reduce the number of decisions you have to make and bring order and structure into a daily life that would otherwise be chaotic. For a patient with Alzheimer's disease, routine can become synonymous with safety. On the other hand, it is important to maintain a normal life as much as possible.

Maintaining patient autonomy: It is important for the patient to be able to maintain their autonomy for as long as possible. This avoids the feeling of depreciation and makes your task easier.

Help the patient maintain her/his dignity: The patient you care for is a human being who shows feelings. Through your work you can give him a sense of insecurity. Avoid talking in his presence about the disease.

Avoid conflicts: Any conflict is unnecessary stress for you as well as for the patient. Avoid showing her mistakes and stay calm. Never forget that this is the disease and the patient himself is not responsible for the errors.**Simplify life:** Simplify the patient's life as much as possible. Avoid giving him things that are impossible to solve.

Keeping a sense of humor: Laugh with the patient, but not with him. Humor helps you cope with difficulties.

Safety: Through physical and memory disorders, the patient risks accidents. You will need to ensure optimal safety.

Help the patient stay fit and healthy: In many cases, this allows the patient's remaining physical and intellectual abilities to be maintained for as long as possible. Proper exercise depends on the physical capacity of the sick person. Seek medical advice.

Help the patient to keep the best of his outstanding skills: Specific activities can help him maintain his dignity and give meaning to his life. Someone who used to be a gardener, a trader, a business owner, will be happy to see their professional skills still appreciated.

Facilitate communication: During the course of the disease, communication with the patient may become difficult. Here are some helpful tips:

- Make sure your eyesight and hearing are not disturbed
- Check and, if necessary, change the diopters and hearing aid
- Speak loudly and clearly to the patient, sitting at eye level
- In contact with the patient show love and tenderness
- Learn to understand the patient's body language: patients whose language is disturbed require a different way of communicating
- Watch / Be aware of your own body language
- Look for combinations of gestures and words that allow real communication with the patient
- Before you start talking, make sure the patient is really listening to you

Use the aide-memoire: In the early stages of Alzheimer's disease, use a few tricks to help the patient memorize and orient themselves and thereby prevent mental confusion. Here are some examples:

- Keeping photo albums with family members with clearly written names in hand so that the patient knows who each one is.
- On the doors, always stick inscriptions or various brightly colored drawings. In the more advanced stages they do not have much effect.

7.1.1. Practical tips for dealing with the problems of Alzheimer's disease

- ***We must not forget that the disease will evolve, and the discomfort will evolve over time.***
- ***This is the reason why person who supervise the patient, must observe the situation, and remain flexible in organizing activities.***
- ***The tips listed below were developed through the experience of the patients' families. You may often find it difficult to follow, but remember that "no one is perfect".***
- ***It is enough to do it as well as possible.***

Bathroom and personal hygiene

The patient with Alzheimer's disease may forget to take a bath, do not need to wash or may forget how to do it. In this regard, you will have to respect his dignity when you offer him help.

Tips:

- If possible, do not change the patient's habits in this area. Make the bath take place in a pleasant and relaxed climate.
- The shower may be simpler than a bath, but a patient unfamiliar with the shower may be afraid. Try to simplify it as much as possible.
- If the patient refuses the bath, try a little later, his condition may change.
- Let the patient take a bath alone, if possible.
- If the patient is modest, it is possible to help him wash, covering certain parts of his body during the bath.
- „Watch his/her safety." For example: non-slip mats can be especially useful in the bathroom.
- If the bathroom is a source of conflict, it is preferable to proceed to his toilet lying down.
- If you run into difficulties, ask another person to fill the tub.

Dressing

A patient with Alzheimer's disease often forgets how to dress or does not perceive the need to change clothes or appears in a poorly dressed in public.

Tips:

- Prepare the clothes by putting them in order or stringing them.
- Avoid clothes with complicated closures.
- Keep the patient's independence as long as possible.
- Do the same repeatedly.
- Choose shoes with non-slip rubber soles.

Incontinence issues

A patient with Alzheimer's disease may lose the ability to understand the time to go to the toilet, forget where the toilet is or does not know what to do.

Tips:

- Set a schedule for going to the toilet.
- On the door write the word "toilet" in bright colors and in bold letters or paste a drawing.
- Leave the toilet door open to be easier for the patient to find.
- Make sure the clothes can be easily removed.
- In the evening, limit fluid intake to a reasonable extent.
- At night, you may need to place a nightstand or a perforated chair near the bed.
- Seek specialist advice.

Cooking

Over time, a patient with Alzheimer's disease may become completely unable to cook (prepare their own food). This is an important problem when the person lives alone because it also involves the risk of accidents. Poor coordination of movements can result in burns and injuries.

Tips:

- Make sure the person is still able to cook.
- Make all necessary installations to ensure its protection.
- Remove sharp objects.
- Make sure that the food is sufficient and adequate. If the patient is unable to feed properly, arrange a home feeding service that can be of real use.

Food Table

Alzheimer's patients often forget to eat or forget how to use cutlery.

Tips:

- Remind patients how to eat.
- Give them food that can be eaten with their fingers.
- Cut their food into small pieces.
- In the advanced stages of the disease it may become necessary to mix all foods.
- Remind patients to eat slowly.
- Remember that the patient may lose the perception of hot or cold and risk burning with food that is too hot.
- If the patient has difficulty swallowing, ask your doctor how you can stimulate swallowing.

Driving a car

For a patient with Alzheimer's disease, driving a car risks becoming dangerous as judgment and slow reactions are disrupted.

Tips:

- Approach the issue with caution with the patient.
- Advise him to use public transport.
- If you are unable to stop him from driving, you may need to consult your doctor or contact the traffic police.

Alcohol and cigarettes

A patient with Alzheimer's disease can safely drink alcohol in moderation, provided he does not take medication. However, due to the risk of fire, cigarettes can present a serious problem.

Tips:

- Supervise the patient who smokes.

Drugs

- Seek the advice of your doctor.

Sleeping disorders

These are patients with Alzheimer's disease who are agitated during the night and disturb the family. This is the main source of exhaustion for those around them.

Tips:

- Try to keep him from sleeping through the day.
- Take long walks with him or make him tired enough during the day.
- Make him feel just as good in bed at night.

Rehearsals

An Alzheimer's patient may forget what he or she wanted to say, ask the same questions, or refers to the same things.

Tips:

- Try to distract her/him by showing her/him or making him listen to the same things.
- Take her/him by the arm and give him the tenderness and security he needs.

Exaggerated addiction

The patient may become very dependent on you and follow you everywhere. This can be annoying and difficult to bear, as it takes away all your privacy. The patient may be afraid that you will not return when you leave him.

Tips:

- When you go out, distract the patient.
- If necessary, ask someone to temporarily take your place so that you can work for a few hours.

Loss of items and charge of theft

Patients often forget where they put their belongings and often accuse their entourage of stealing their lost objects. This behavior shows a feeling of insecurity due to loss of memory control.

Tips:

- Try to find out if the patient is hiding objects in certain places.
- Duplicate frequently lost objects, such as keys.
- Check the contents of the trash before disposing of it.
- To respond to accusations, adopt a calm attitude.
- Admit with the patient that the object is lost and help him look for it.

Delusional ideas and hallucinations

Delusional ideas and hallucinations are not uncommon in Alzheimer's disease. A delusional idea is a fixed idea: for example, the person thinks that his entourage is a danger. For the patient, this is a reality, it is a source of anxiety that can train him in his desperate attempts to protect himself. During hallucinations, the patient sees or hears things that do not exist, such as the shadow of the feet of his bed or people living in the room.

Tips:

- Do not try to take the patient out of his or her own reality. If he is worried, try to calm him down with a calm voice. You can also calmly take his hand to calm him down.
- Distract him by pointing to something else in the room.
- Ask your doctor if these problems are due to the medicines you are using.

Lost

This is a serious problem that you risk facing. People with Alzheimer's disease often leave home or run away. By the time they run away, they risk getting lost. When a patient is alone in a public place, we must look after her/his safety.

Tips:

- When leaving the house, the patient must wear an identity card.
- Arrange your home in such a way that it is difficult for the patient to get out.
- When you find the patient, avoid being noisy. Speak to them calmly, tenderly and understandingly.
- Always keep a recent photo of the patient and always remember how he is dressed in case you need to give his signals.

Violence and aggression

The patient may become unpleasant, aggressive, or violent. These behaviors can occur for various reasons, for example because he has lost social contact and judgment, because he cannot express his negative feelings, or because he can no longer understand and interpret the activities of others. For those around you, this is one of the most difficult issues.

Tips:

- Stay calm without showing fear or apprehension.
- Try to draw the patient's attention to a calming activity.
- Pay more attention to it.
- Try to find the cause so that you avoid it in the future.
- If violence becomes a common problem, you need help. Talk to your doctor about how to treat your patient.

Depression and anxiety

These patients may become depressed, may shut themselves in, may give the impression of gloomy beings, speak, think, and act slowly. This can influence daily activities, as well as appetite.

Tips:

- Seek the advice of your doctor, psychologist or psychiatrist.
- Try to give more love to the patient, more support.
- Do not expect depression to go away immediately

7.2. What Mental Activities Can We Do?

7.2.1. 7 Mind Stimulating Activities & Cognitive Games for Seniors

There are a lot of different reasons that your elderly loved one might have cognitive issues but keeping their brain active and engaged can help to make sure that you slowdown that deterioration. Some of these activities might help and they allow you and your loved one to have fun together. The following mind stimulating activities provide ways to keep seniors sharp, helping to improve memory, problem-solving, creativity, and other cognitive functions [3]:

Word Games

Word games serve as effective and fun ways to engage the mind. For seniors, puzzles help to improve memory, word recall and other functions in the brain. If your loved one enjoyed word plays books in the past, such as word searches, Sudoku, and crossword puzzles, they may still enjoy them. They may not be able to still do the more advanced word play activities they enjoyed in the past, but if you find easier ones that can help quite a bit. Look for books that have larger print and that are geared toward a younger vocabulary if you can.

Caregiver Tip: Encourage your loved one or patient to complete crossword puzzles found in the daily newspaper or pick one up from the store. This type of cognitive activity provides entertainment and keeps the mind active and sharp!

Games and Puzzles

Games and puzzles are also good for your loved one, but only if they can keep up with them. Choosing games or puzzles that are too advanced or too complicated may frustrate your loved one, causing them to give up. This is another occasion where finding puzzles and games intended for children may help your loved one to engage more fully. Cards used for preschoolers, in which the patient indicates what they see, may also help to recognize concepts. You may also consider creating your own games and puzzles with items or familiar faces that your loved one may recognize, or that could help him in remember faces and facts about his personal life.

Caregiver Tip: Something you might want to consider as your loved one's family caregiver is tossing out the rules for your elderly loved one. It doesn't matter if the game, puzzle, or other activity is done right necessarily, it's more about engaging your loved one. If they're able to be a little bit creative and stay engaged, then it might be worth it to stop worrying about whether the activity is being done properly or not. You might just find that you and your loved one have a lot more fun that way, too.

Card Games

Simple card games such as Poker, Solitaire, Go Fish and Memory Match can help to improve cognitive function in seniors. Card games stimulate parts of the brain responsible for logical problem-solving and memory retention, along with other functions.

Caregiver Tip: Play card games with your loved one or patient after dinner to keep their mind sharp.

Chess & Strategy Games

Strategy games such as checkers and chess stimulate multiple parts of the brain and are widely used for educational purposes. It is believed that the chess provides the following benefits:

- Likely to raise an individual's IQ
- Helps to prevent Alzheimer's and other forms of dementia
- Exercises both sides of the brain

- Increases creativity
- Improves memory, concentration, problem-solving, reading, and decision-making skills

Reading

Even if your elderly loved one has cognitive issues, books and magazines can still engage them and help keep their brain active. Enjoying a good novel, reading an article on the web, or catching up with the daily news not only keeps seniors informed and entertained, but it helps to improve a variety of cognitive functions. Reading sparks imagination and forces the brain to create images to match the words written on paper, making it one of the most entertaining and effective ways to exercise the brain. Depending on your loved one's current situation, they may find themselves enjoying books and magazines that may seem below their level. Some elderly loved ones even enjoy children's books because they're easier to read and to understand.

Caregiver Tip: Recommend a good novel for your loved one or patient to curl up with before bed.

Activities Involving the Use of Hands

Activities that focus on hand-eye coordination and creativity such as knitting, sewing, playing an instrument and even video games help seniors exercise the brain.

Caregiver Tip: Consider using a video game console for your patient or senior family member.

Physical Exercise & Healthy Lifestyle

Maintaining a healthy lifestyle is vital for improving your memory. Just as our muscles need exercise to grow, so do our brains. Studies by the Alzheimer's Research & Prevention Foundation have shown that exercising regularly can reduce the risk of developing cognitive impairment by up to 50% and - not least - can reduce deterioration in those in whom the disease has already occurred. In practice, physical activity stimulates the brain both to maintain old neuronal connections and to create new ones.

What is needed? At least 150 minutes of moderate exercise per week: preferably alternating cardio and muscle mass consolidation activities. For starters, walking and swimming are fine. It is also important to include exercises that involve balance and coordination of movements, such as yoga or tai chi. For seniors with limited mobility, there are still many ways to stay active and keep the heart rate up, whether it's walking, light gardening, housekeeping, stretching or even meditation. Exercise releases endorphins in the brain and has also been shown to improve one's mood, vitality, alertness and overall feelings of well-being.

Alzheimer's is also called „brain diabetes": inflammation and insulin resistance damage neurons and inhibit communication between brain cells. By correcting and making your eating habits healthier, you can reduce inflammation and thus protect the brain.

What are the main indications?

- Reduce sugar;
- Lots of fruits and vegetables;
- Supplementing Omega3 fats, which seem to have a positive impact in Alzheimer's, helping to reduce beta-amyloid plaques.

7.2.2. 15 Brain Exercises to Help Keep You Mentally Sharp

Brain exercises research has shown that there are many ways you can hone your mental sharpness and help your brain stay healthy, no matter what age you are. Doing certain brain exercises to help boost your memory, concentration, and focus can make daily tasks quicker and easier to do, and keep your brain sharp as you get older.

The brain is involved in everything we do and, like any other part of the body, it needs to be cared for too. Exercising the brain to improve memory, focus, or daily functionality is a top priority for many people, especially as they get older. That said, people of all ages can benefit from incorporating a few simple brain exercises into their daily life, which we'll explore in more detail in this article.

Let's take a deeper dive into 15 evidence-based exercises that offer the best brain-boosting benefits [4]:

Look at family photos

Looking at family photos in a quiet envoirment may help patients fostering their memory and increasing recall. In implementing this activity is important to choose photos which represent significant events for the patients. Moreover, photos should include family member's name clearly written so that the patient knows who each one is.

Have fun with a jigsaw puzzle

Working on a jigsaw puzzle is an excellent way to strengthen your brain. Researchers has shown that doing jigsaw puzzles recruits multiple cognitive abilities and is a protective factor for visuospatial cognitive aging. In other words, when putting together a jigsaw puzzle, you have to look at different pieces and figure out where they fit within the larger picture. This can be a great way to challenge and exercise your brain.

Try your hand at cards

Stimulating activities for adults and a quick card game can lead to greater brain volume in several regions of the brain. The game of cards, in general, could improve memory and thinking skills (solitaire, bridge, gin rummy, poker, hearts and crazy eights).

Build your (patient) vocabulary

A rich vocabulary has a way of making patient sound smart. Researchers shows that many more regions of the brain are involved in vocabulary tasks, particularly in areas that are important for visual and auditory processing. To test this theory, try this cognitive-boosting activity:

- Keep a notebook with you when you read.
- Write down one unfamiliar word, then look up the definition.
- Try to use that word five times the next day.

Dance your heart out

Learning new dance moves can increase patient brain's processing speed and memory. In other words, patient can bust a move on the dance floor and his/her brain will thank you. Want to test it out?

- Give one of these dance activities a try:
- Take a salsa, tap, hip-hop, or contemporary dance class.
- Try a Zumba or jazz exercise class.
- Watch an online video with fun dance moves you've always wanted to learn.
- Grab a partner and learn to ballroom dance.
- Gather your friends and go line dancing.

Use all your senses

Give your senses and your brain a workout, try doing activities that simultaneously engage all five of your senses (try baking a batch of cookies, visiting a market, or trying a new restaurant while focus on smelling, touching, tasting, seeing, and hearing all at the same time).

Learn a new skill

Learning a new skill is not only fun and interesting, but it may also help strengthen the connections in your brain becasue a new skill can help improve memory function in older adults.

Teach a new skill to someone else

One of the best ways to expand your learning is to teach a skill to another person. After you learn a new skill, you need to practice it. Teaching it to someone else requires you to explain the concept and correct any mistakes you make.

Listen to / or play music

Listening to happy tunes helps generate more innovative solutions compared to being in silence, which means, cranking up some feel-good music can help boost patient creative thinking and brain power. That’s why nobody’re never too old to start playing an instrument like the piano, guitar, or even the drums.

Take a new route

Choosing a different route to get to work each week or trying a different mode of transport, like biking or using public transport instead of driving..

Meditate

Daily meditation can calm patient body, slow his/her breathing, and reduce stress and anxiety. Find a quiet spot, close your eyes, and spend five minutes meditating each day.

Learn a new language

According to numerous studies, bilingualism can contribute to better memory, improved visual-spatial skills, and higher levels of creativity. Being fluent in more than one language may also help you switch more easily between different tasks, and delay the onset of age-related mental decline.

Take up tai chi

It’s no secret that tai chi can benefit your health in many ways, including patient mental health. Plus, it can also help center you when life seems out of balance.Taking up a regular practice of tai chi can help reduce stress, enhance sleep quality, and improve memory.

Beginners do best by taking a class to learn the different movements. But once patient know the basics, he/she can practice tai chi anywhere, anytime.

Focus on another person

When patient interact with someone, it is benefical to take note of four things about other person (observe the color of their shirt or pants, if they are wearing glasses? What color is their hair?. Write down what he/she remember about those four details.

The bottom line

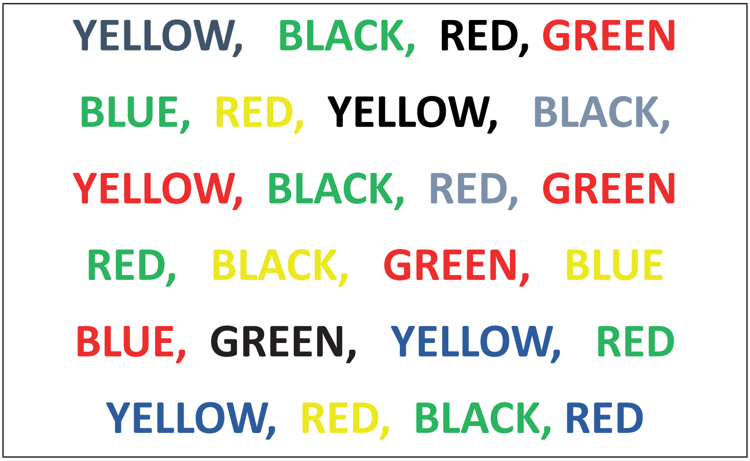
Focusing on patient brain health is one of the best things we can do to improve patient concentration, focus, memory, and mental agility, no matter what age he/she has.

7.2.3. Image Colors and Words

Color words

Other exercises that can be performed are as we see in the below image that different colors are reproduced on different words that mean colors. The exercise is that you have to say out loud the colors you see, one after the other, without being misled by the written word. This will train both hemispheres of the brain, the one that responds to reading and the second that responds to color perception. It may be difficult at first but this exercise is very effective in preventing Alzheimer's disease [5].

- Creating a connection between the 2 hemispheres of the brain;
- It improves the ability to concentrate and change the object of attention.



YELLOW, BLACK, RED, GREEN
BLUE, RED, YELLOW, BLACK,
YELLOW, BLACK, RED, GREEN
RED, BLACK, GREEN, BLUE
BLUE, GREEN, YELLOW, RED
YELLOW, RED, BLACK, RED

Figure 7.1. Color words [5]

Tabelul Schulte

To complete the exercise, focus on the number in the middle, ie 19. The task is to find shoulders that contain the number 1 in the rest of the table in their order of growth. For this, it is best to focus on each digit. You can make your task more difficult by making such a table with the number indicated in the random model. This exercise will train the speed with which the brain analyzes the information and will also improve your peripheral vision [6].

17	9	24	25	12
8	6	1	15	7
23	21	19	3	11
20	13	4	16	5
2	14	10	18	22

Figure 7.2. Tabelul schulte [5]

Fingersprint

It is a simple exercise that is performed with the patient’s fingers.

- First put the fingers of the right hand in the position of peace;
- Then the fingers of the left hand in the ok sign.

In what follows changing hands the same signs are performed several times. Both signs cannot be achieved due to lack of synchronization, so it is recommended that the patient train in order to be able to perform the signs with both hands at the same time.

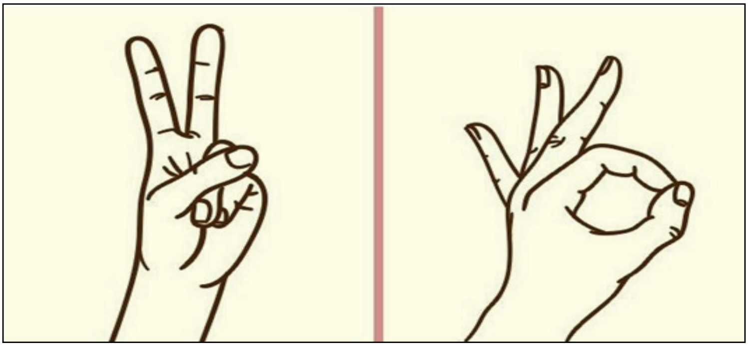


Figure 7.3. Fingersprint [5]

The synchronous letter

The synchronous letter trains the memory very well because both hemispheres are activated simultaneously.

To perform this exercise:

- take a sheet of paper in each hand;
- you have to draw geometric figures with both hands at the same time.

Likewise, you can write letters or words of the same length, with both hands at once. The patient's movements must be synchronized.

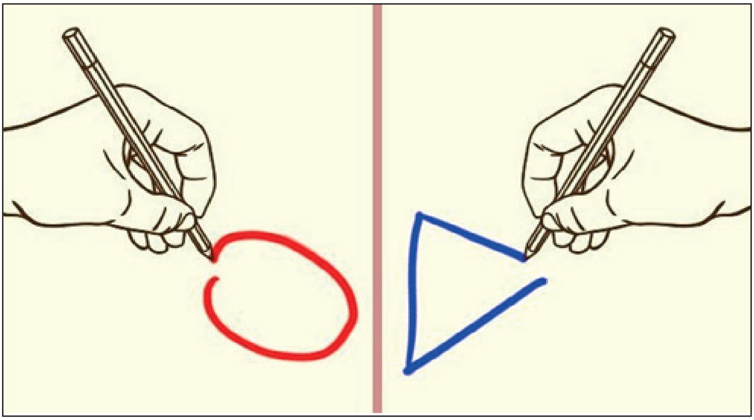


Figure 7.4. Synchronous letter [5]

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CHAPTER 8

PATIENT’S PERSONAL CARE

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Chapter Content

8.1. Who Will Be Responsible?

They have difficulties in living their daily lives on their own from the first diagnosis of Alzheimer’s disease. In this regard, patients should not be left alone and should live with a caregiver. However, one of the most basic problems is often who will be the caregiver. Those who have the power to pay a certain fee for the caregiver can provide care at home. Apart from this, it can be ensured that he/she stays in private daycare centers. However, a first-stage patient staying in a nursing home can be an important source of problems. If a healthy spouse is present, he or she will often be a caregiver. If possible, it is always recommended to be cared for at the patient’s home. The patient may experience some problems outside his/her own home. Another solution is to live in the house of one of the relatives of the patient. It is perhaps one of the most difficult situations. However, it should be determined who or who will be responsible for the patient considering that patients at this level cannot be alone.

As mentioned above, there is no problem in leaving the patients alone for a short time, provided that the safety at home is taken in the first stage.

8.2. Personal Hygiene of the Patient

Personal care of the patient is one of the greatest difficulties, especially in the intermediate and advanced stages. Bathing, dressing, and incontinence begin to deteriorate in the early stages of dementia. Therefore, Alzheimer’s patients may lose confidence in their own physical feedback.

BATHING

Bathing and dressing are private activities that require privacy. Many people do not want to undress in front of others. They may also feel embarrassed or humiliated since they need help from someone else. Especially if they are incontinent, they may be embarrassed and may refuse to take a bath or change their clothes to hide the problem.

What to do in this situation? [1]

- Pull down blinds or close curtains and doors to create a sense of privacy
- Cover the mirrors if they don’t recognize themselves.
- A person with dementia may feel uncomfortable. The room may be too hot or cold or it may create a feeling of claustrophobia.

They don't want to take a bath or have a shower every day. In the past, many people did not take bath as often as they do today. It is important that you do not impose your own values on how often the person should have a bath. Make sure the bathroom is warm enough and how often the person wants to have a bath.

- Especially in the evening, provide adequate lighting in the bathroom.
- It can be helpful to have soft music in the background to create a calming and relaxing atmosphere.
- Consider the most comfortable time of the day for your patient and the type of bath, shower or sponge he/she are used to.
- For people with dementia, activities such as undressing, washing, and brushing teeth can be complex tasks that require many steps. In some people with dementia, the perception of hot and cold water may be altered due to damage to the part of the brain that regulates the "internal thermostat." They may feel a different sensation from water.
- Break down tasks into simple steps, gently explaining each step. Use simple, respectful language.
- Try to offer limited options – for example, "*Would you like to take a bath or shower?*" or "*Would you like to take your bath now or before you go to bed?*"
- Let the person feel the water before starting to have bath. Sometimes lightly pouring water over their hands will let them know that the water isn't too hot. Asking the person, "*Is this temperature, okay?*" can be reassuring and calming.
- Encourage the person to take on many things about themselves. But don't be too persistent.
- Arrange soap, wash cloths, towels, and clean clothes in order so they can use them as needed.
- Some patients may have fears about water. Fear of water can sometimes be a problem. A person with dementia may not be able to measure the depth or temperature of the water and may be afraid to step into it. He/she may have the fear of falling. Feeling out of control and powerless can prevent a person from cooperating in taking a bath. A person with dementia may fear

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drowning, especially if water is running over his/her head.

- Prepare the bath in advance. Check the water level. Some people prefer only a small amount of water in the bath. Others prefer it more.
- Try separating the hair wash from having the bath. Some people with dementia associate having bath with washing their hair and are upset because they are afraid of water being spilled on their head.
- Give plenty of time and encouragement to help the person maintain their skills.
- A hand-held shower head can be attached to the tap.
- Having a place with special bathroom fixtures, such as a railing, can make bathing easier.

DENTAL CARE

Poor dental health can affect a person's comfort, appearance, eating, nutrition, behavior, and general health. Every person with dementia needs an individualized preventive approach for his/her dental care as soon as he/she is diagnosed with dementia.

People with dementia are susceptible to dental problems for a number of reasons, including:

- **Decreased saliva.** Taking medications that reduce saliva production by the salivary glands. Saliva is essential for maintaining a healthy mouth and preventing the onset of tooth decay and other mouth lesions. Even if the patient is not taking medication, salivary flow may be reduced.
- **Help the person drinking plenty of water or spray their mouth with water using a spray bottle.** There are some medications and products available that can help. Discuss them with the physician and dentist.

How do we protect the dental health of someone with dementia? [1]

- Assistance in dental care. Reminding and helping people brushing teeth and denture care.
- Reduce sugar intake. For people with natural teeth, monitor and reduce sugar intake as needed.
- Use fluoride. Use fluoride regularly on natural teeth. This in-

cludes fluoridated tap water, toothpastes, mouthwashes, and gels. Fluoride is available in toothpastes.

- All surfaces of all teeth, especially cheek surfaces, should be brushed with a soft toothbrush.
- Many people with dementia are unable to verbally express their discomfort or pain. They rely on their families and caregivers to understand any behavioral changes that could indicate dental issues, such as not eating or refusal of oral hygiene care, or other behavioral issues.
- If the person with dementia is clenching or their lips and cheeks and spasming, you can use a toothbrush that tilts back 45 degrees. Slide the bent brush into the corner of the mouth to prevent muscle spasms and help unblock the cheek.
- Brushing and removing dentures may be easier from the front, side, or back. Try to find what works for you and the person with dementia.
- Regular dental check-ups. Visit a dentist who understands and is experienced in caring for someone with dementia.

Denture care [1,2]

- The best way to take care of dentures is to clean and brush them daily. Rinse dentures after each meal and brush thoroughly with a hard toothbrush, nail brush or denture brush, and plain soap and water.
- Place a face washer in the sink and fill it with 5cm of water while cleaning the denture so that the denture does not crack if dropped.
- Denture cleaning tablets are not required but can be used if desired. Physical cleanliness is essential.
- Soaking dentures overnight is no longer recommended. Rinse them and let them dry on a small hand towel.
- All dentures of people with dementia must be marked for identification.
- Care should be taken if there are partial denture clips. It can be very damaging to the oral tissues and tongue and may be more difficult to remove.

8.3. Other Hygiene Problems

Toilet

A person with dementia may need help with toileting. Many people with dementia face loss of bladder or bowel control (incontinence). In order to overcome toilet problems, ***follow these recommendations:***

Remove Barriers. Make sure the clothes are easy to remove. Provide a open path to the bathroom. Create visible reminders. Hang a toilet sign or picture on the bathroom door and use colourful toilet seat covers and bathroom rugs.

Remind me. Encourage the person to use the toilet regularly. Watch out for restlessness that may indicate the need to leave.

Monitor incontinence. Identify when the accidents occur, then prepare accordingly. In case that it occurs every two hours, direct the person to the toilet before that time. Reduce fluids in the evening or schedule bathroom visits in the middle of the night. Put padded underwear or adult panties or something else on a nightstand.

Make sure they are clean and dry and that their underwear is changed as needed.

Be sure to carefully wash the clothes with warm water and dry them thoroughly before putting on clean clothes. Be mindful of dignity and respect when providing support to the toilet. Consider the toilet process, the toilet environment, and health and biological considerations. In general, people living with dementia may be more appropriate if, for example, they are monitored for signs of leakage or incontinence, if they have regularly scheduled bathroom visits and if they take a clearly visible bathroom, and if they avoid caffeine and fluids in the evening.

Help the person maintaining a sense of dignity. Provide reassurance to reduce embarrassment.

Shaving

Firstly, you may need to remind the person with dementia to shave daily. If they're used to an electric shaver, they'll likely be able to continue shaving longer without supervision. If they are used to a traditional razor and start cutting themselves regularly, you will need to supervise the shaving and even do it for them.

Ear care

Earwax buildup can be a problem for some people and can lead to unnecessary hearing impairment. Talk to the physician about the best way to deal with earwax.

Clothing Hygiene

Changing clothes is important for hygiene and personal freshness. Encourage the person to do so regularly. At the end of the day, it may mean gently removing dirty clothes and replacing them with clean ones. In order to alleviate the workload, try to choose clothes that are easy to wash and need less ironing. Most people like to be complimented on their looks, especially when wearing new clothes or getting a new haircut. It is important that a person with dementia also has this experience.

Nails and toenails care

A person with dementia may forget or have trouble cutting their nails. As uncut nails can cause problems, it is important to do this regularly. Consider whether the person enjoys painting their nails and getting a manicure.

Hair Cleaning [1,3,4]

You may need to spend time finding a way to wash hair that is comfortable for the person with dementia. Some people can become very distressed by washing their hair. A visit to the hairdresser or a hairdresser coming home may be a better alternative. Many people with dementia continue to enjoy getting their hair cut and styled, and it can continue to be an enjoyable experience.

8.4. Dressing

People with dementia may have problems with dressing, undressing, ambient temperature, and clothing that can be worn outside and at home. Getting dressed can be a very complex and overwhelming task since there are so many steps. Helping a person with dementia getting dressed can be extremely time consuming and emotionally exhausting, especially if the person is uncooperative. Each person with dementia may react differently as an individual. An approach is needed that works best for both you and the person with dementia.

Reasons why a person with dementia may have trouble getting dressed

Physical or medical reasons

Depression or a physical illness can cause a loss of interest in personal hygiene. There may have been changes in gross motor skills that cause problems with balance or walking. The changes may be related to fine motor skills, which can cause problems with buttoning or closing a zipper. A person with dementia may have visual impairment. The adverse effects of some medications can cause dizziness or stiff joints.

What to do?

- Their vision or glasses should be checked: The person may be depressed, especially if they do not want to get up often in the morning or get dressed.
- It is important to encourage the person with dementia who has problems deciding what to wear to choose their own clothes. However, for many, even making simple decisions can be difficult.
- xSimplify the number of choices. For example, offer two outfits to choose from, or ask him/her to choose between a white shirt and a blue shirt.
- Put the clothes on the bed in order. Clothing should be arranged in order.
- Try layering light-colored clothing over a dark-colored bedspread. For someone with vision problems, contrasting colors can help a person with dementia see items of clothing from the background color of the bedspread.

Forgetting to dress

Some people with dementia can’t remember whether they got dressed or not. They may also forget to change their clothes, put them in the wrong order, or dress in multiple layers. They may realize they have a cloth, but have no idea what part of the body it covers.

What to do?

- Careful directions or reminders can help a person dress independently.
- Arrange the clothes in a pile with the first cloth to be worn on top.

- Try using the task distribution technique. It involves breaking the task down into simple and manageable steps and doing them step by step. You may need to gently remind the person each step of the way or do a few steps yourself. Giving reassurance and praise for each successful step will make the task more enjoyable for both of you.

Environmental issues

Noise, people, bright lights, and clutter in the room can be distracting for a person with dementia trying to get dressed. Some older people, and especially those with dementia, have different temperature needs. While the person with dementia may find the temperature quite comfortable, sometimes you will feel like it's overwhelmingly hot inside the house.

What to do?

- Store out-of-season clothes outside of the wardrobe.
- Make sure the room is warm enough for the person with dementia.
- Provide adequate lighting. Also, make sure that the light in the wardrobe is at the same brightness as the light in the room, so that the person does not have to get used to different light levels.

Lack of privacy

Dressing is a very personal and private activity for most of us. Many people have never dressed or undressed in front of anyone else, and it can be an uncomfortable experience. It also conveys the message that when a person needs help, they can no longer take care of themselves. Accepting this loss of independence can be very difficult.

What to do?

- Close the door and pull down the louvers to create a sense of privacy.
- In case that the person can manage most of the tasks, it is much better to leave them to him/her and only intervene from afar when necessary.
- Take care of dignity, respect, and choice when providing support with dressing. They can dress more independently if given selective choice and simple verbal instructions during the dressing process and if they dress in comfortable, safe areas.

Impaired senses

The person may want to wear many layers of clothing, regardless of the weather. Some people with dementia may have impaired judgment and sense of heat and cold and may want to wear layers of clothing regardless of the weather.

What to do?

If extra clothing is not causing any discomfort, it is easier to leave it alone. Packing extra clothes and putting them away can also be a solution.

Problems with frequent undressing

Some people with dementia may undress frequently. It can be embarrassing and inappropriate, but they may no longer understand what's appropriate and often don't do it to be provocative.

Clothing Choice Problem

- Appropriate selection of clothes and shoes. It is very important to protect the individuality and style of dressing of a person. Introducing clothes that are very different from a vintage style can cause more trouble than it's worth.
- Choose clothes that are washable and do not require ironing. For some people, buttons, snaps, hooks, zippers, and belt buckles are very difficult to manage. They can be replaced with an adhesive type of tape that can be purchased at any fabric store.
- xDense and bright patterns on clothing can be distracting. Choose clothes with simple patterns and contrasting colors as them are easier to see for many people.
- Choose shoes without laces. It is easier to wear than lace-up shoes. Make sure the shoes have non-slip soles.

Other issues [1,3,4]

- In the past, many people did not change their clothes as often as they do today. It is important that you do not impose your own values on how often clothes should be changed.
- It's often better to buy a few of the same outfit and let them wear what they want rather than arguing with someone who wants to wear the same outfit every day.
- Being reminded to change your clothes can be an embarrassing and humiliating experience. Therefore, do not say that their clothes are dirty. Instead, say "Would you like to change your clothes?".
- The extra time spent maintaining independence is well worth it. Being able to dress by yourself can make a person feel more independent and improve feelings of pride and self-esteem.

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CHAPTER 9

FOOD AND NUTRITIONAL PROBLEMS

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Chapter Content

9.1. Introduction

Mealtimes offer us the opportunity to share meals together as well as to spend time with our family and friends. Mealtimes can sometimes be stressful when caring for someone with dementia. Memory loss and reasoning problems can cause difficulties with eating and nutrition for many people with dementia. There are many ways to improve the situation.

Loss of appetite [1]

Forgetting to chew and swallow, poorly fitting dentures, insufficient physical activity, and being embarrassed by difficulties can cause loss of appetite.

What to do? [1,2,3]

- Consult your physician to make sure there is no treatable cause for your loss of appetite, such as acute disease or depression.
- Offer meals at regular times each day.
- Let the person eat when hungry.
- Encourage physical exercise.
- Provide balanced meals to prevent constipation.
- If medications allow, try liquids such as a glass of fruit juice before a meal to stimulate the appetite.
- Try to prepare familiar foods, especially favorite foods, in familiar ways.
- Encourage eating all or most of one food before moving on to the next. Some people may be confused when flavors and textures change.
- Try making mealtimes simple, relaxed, and calm. Make sure you leave enough time to eat. Helping a very disabled person can take up to an hour.
- Consult a physician if there is significant weight loss (like 2.5 kg in 6 weeks)
- Ask your physician related to vitamin supplements.

If he/she has overeating or an insatiable appetite, what to do? [1]

- Leaving junk food on the table may be enough to satisfy some.
- Try 5-6 small meals each day.
- Have low-calorie snacks like apples and carrots on hand.

- Consider whether other activities, such as walks or increased social contacts, would help.
- Lock some food in cabinets if needed.
- If the sweet craving is too much, what to do? [1]
- Check medications for adverse effects. Some antidepressant medications can cause sweet cravings.
- Try a milk shake, eggnog, or low-calorie ice cream.

Mouth, chewing, and swallowing problems

Some causes of problems with eating may be related to the mouth. Dry mouth or oral discomfort from gum disease or improper dentures are common problems.

What to do?

- Get a dental exam for the gums, teeth, and dentures.
- If dry mouth is causing problems, moisten food with sauces and dressings.
- For chewing problems, try applying gentle pressure to the lips or under the chin, tell the person when to chew, demonstrate chewing, moisten food, or give small bites, one at a time.
- For swallowing problems, remind the person to swallow with each bite, tap their throat lightly, check their mouth for swallowing, avoid giving hard-to-swallow foods, eat smaller bites, and wet food.
- Consult a doctor if choking problems develop.

Problems at the table [4]

Pouring a glass of juice into a bowl of soup, rubbing oil on a napkin, or eating dessert with a knife indicates that a person with dementia is having difficulty at the dinner table.

What to do?

- Serve one meal at a time and remove other distractions from the table, such as extra cutlery or table decorations.
- Make sure the dishes are flat and a different colour from the plain tablecloth.
- If the cutlery is too difficult to use, serve food by hand.
- Eat with the person with dementia so they can imitate you.
- Make sure he/she is not rushed.
- Keep ambient noise and activities to a minimum.

- Make sure there is sufficient lighting.
- Serve familiar foods.

Other issues

Keep eating simple. If that gets tricky, not all food has to be eaten with cutlery. Snack foods can be a nutritious and easy alternative.

Keep in mind a person's food history. They may have always had a small appetite, eating insatiably. Monitor food temperatures. Although hot food may be more appetizing, some people with dementia have lost the ability to judge whether food is hot or cold. Be careful not to use Styrofoam containers that not only hold heat for long but also tip over easily.

What to do?

- Hiding spoiled food or not eating it regularly may be signs that someone who lives alone needs more support.
- Many people with dementia do not get enough fluids because they may forget to drink or may no longer recognize the feeling of thirst. Be sure to offer water, juice, or other liquids regularly to prevent dehydration.
- Many eating problems are temporary. However, their eating problems will increase as the person's abilities deteriorate.
- Exercise dignity, respect, and choice when providing support in eating. Generally, people with dementia are more likely to eat if they are given choices, eat with others and in a quiet, relaxing, home-like environment, maintain oral health, and are provided with adaptable food and utensils.

9.2. The Importance of Good Nutrition

The type of food we eat affects our health and quality of life. People who are malnourished get sick more often and recover more slowly from injuries and diseases. Malnutrition is a major health problem for many older people.

Daily nutritional balance

The nutritional requirements of someone with dementia will be similar to other people their age. However, some people with dementia experience increased physical activity, such as pacing. It means they will need larger amounts of food to prevent them from losing weight.

What to do? [6]

- Enjoying a wide variety of nutritious foods
- Eating at least three meals a day

- Drinking lots of water
- Eating plenty of vegetables (including legumes) and fruit
- Eating plenty of cereal, bread, and pasta
- Eating a diet low in saturated fat
- Choosing foods low in salt and using salt sparingly
- Including foods high in calcium in the diet
- Using added sugars in sparingly

9.3. Common Nutritional Problems

They may forget eating.

What to do? [1,3,4]

- An alarm clock or a phone call can be a useful reminder at meal-times.
- Snacks that are easy to eat and do not need to be kept in the refrigerator can be left where they can be seen easily.
- They cannot prepare food for themselves. Preparing or cooking meals for themselves can be especially difficult for people with dementia who live alone.
- Meals should be shared in social settings as much as possible.
- It is important to have a support person at home to help with preparing, serving, and sneaking meals.
- Prepare and/or dine together with family and friends.
- When it comes to dining out, first check to see if the person with dementia would be comfortable with the venue and food.

If the person with dementia drinks too much alcohol [5]

Alcohol can stimulate appetite and add to the pleasure of eating. However, too much alcohol can displace food and people may be at risk of malnutrition. In case that a person with dementia drinks too much alcohol, it can be difficult to change their drinking habits.

What to do?

- Make sure they are well fed
- Do not let them drink on an empty stomach
- Offer non-alcoholic beverages.

In order to fix some other problems with eating:

- Prepare a plate of nutritious and attractive foods that can be grasped with fingers.

- Make sure food is accessible. Put on a flat plate without a pattern so that the food can be seen clearly. Make sure the plate is within easy reach.
- Do not use complex table settings and avoid mixing lots of different cutlery, plates, glasses, food, and drinks.
- Serve only one plate of food at a time.
- Impairment of the senses of taste and smell can reduce appetite. The preparation of delicious, strongly flavored, and aromatic foods can help.
- Allow time for memory to respond.
- Initially, it may be necessary to assist the fingers to move the food from the plate to the mouth.
- Eat together so the person with dementia can imitate you.
- The types of food offered should take into account the person's culture and past eating habits.

Eating in advanced stages of dementia [2,6]

- It is common for people in the advanced stages of dementia to lose a significant amount of weight. People may forget how to eat and drink or may not recognize the food they are given. Some people become unable to swallow properly.
- The provision of nutritional supplements may need to be considered. In case that a person has difficulty swallowing or does not consume food or drink for a significant period of time and their health is being affected, nutritional supplements may be considered for consumption other than the oral.

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CHAPTER 10

DAILY LIFE ACTIVITIES AT HOME WITH INDIVIDUALS WITH DEMENTIA AND ALZHEIMER’S

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Chapter Content

10.1. Introduction

It is important to care for and encourage the person with Alzheimer's or dementia to always function to the best of their abilities. It is required to let them do as much as possible for themselves (perhaps with your guidance). It not only gives them a sense of confidence that reinforces their self-confidence and willingness to do things, but it also helps them retain their abilities for as long as possible. In case that you start doing things for them that they can do, they lose their ability to do. This is called "excessive disability". It means that the loss of ability is caused by something other than dementia.

For instance, in case that the person has trouble buttoning their shirt and you button it for them, that person may stop buttoning the shirt. While they can still button up their shirt (even if slowly), they may no longer remember because they no longer use time-related steps. The loss has no physiological cause, it is due to lack of application. This is an extreme injury. In order to minimize this, it is important that you let them do it for themselves as much as possible, even if it's frustrating.

Much can be carried out around the home to make it as easy as possible for the person with dementia to continue doing things on their own. If the person is having trouble with a task, see whether there is anything you can do to make it doable rather than taking it away [1]. For example, if the person has always washed the laundry, you may need to help him /her sort it out before continuing. If the person is always setting the table, maybe you should put the cutlery on a tray instead of having him/her choose from the drawer [2].

If the person seems unable to do something since, they cannot find the necessary materials, try using signs and tags to help them. If you find that they have a hard time finding their coffee cups so they can't put their own cups, try labeling the cupboard where the cups are located. This may be helpful enough to get the person moving again. If the "Coffee Cups" tag doesn't work, you can try a picture of a coffee cup instead. If a person has difficulty adjusting the dials on the washing machine, an arrow can be attached to the machine indicating the correct position [3].

If you enable your patient and you to spend the day more productively and happily by doing indoor activities, the negative behaviors caused by the disease may decrease or sometimes disappear. Daily pursuits can also help him/her retain his/her remaining skills, build confidence, and become more engaged. They also contribute to the close contact and rapprochement of the patient with the patient.

A person with Alzheimer's or other progressive dementia will need the help of a caregiver to organize the day. Structured and pleasant activities often reduce restlessness, improve mood, structure time, provide a sense of commitment, usefulness, achievement, and dignity, increase feelings of security and togetherness, and help reducing behaviors such as wandering [3].

Planning activities for someone with dementia work best when you are constantly exploring, experimenting, and adapting. Write down which of the activities he/she does seem happy. Include more activities like this in the next process. Considering these, both your patient and you can have a pleasant time. With creativity, flexibility, and problem solving, you will be able to adapt your daily routine to support these changes [4].

10 Tips for Activities at Home [1,4,5] (The following activities are suitable for people with early and middle stage Alzheimer's)

- 1. Be flexible and patient.
- 2. Encourage participation in daily life.
- 3. Avoid correcting the person.
- 4. Help the person staying as independent as possible.
- 5. Offer opportunities to choose.
- 6. Simplify instructions.
- 7. Establish a familiar routine.
- 8. Respond to the person's feelings.
- 9. Simplify, configure, and control.
- 10. Provide encouragement and support.

10.2. Activities That Can Also Be Done at Home

Consider that the patient with Alzheimer's has different abilities and skills in the early, intermediate, and advanced stages of doing housework.

In the early stage of Alzheimer's, the patient with Alzheimer's can do daily housework, such as cleaning, cooking, preparing breakfast, together with the caregiver. Do not say to the patient "stop it, let me do it". Do not hinder if he/she starts doing the activities that he/she will do himself. Don't criticize him/her when he/she is not good enough at what he does. When he/she says, "I can't do these well anymore," tell him he/she can do well but needs some help.

10.2.1. Helping with Simple Jobs

Washing the Dishes

Materials: Bowl of warm soapy water, wash cloth, towel for drying, absorbent mat for drying rack and "dirty" dish set

Application: Put the washing and drying utensils on the table with the "dirty" dishes. Ask the person to help by washing the dishes. If appropriate, ask a second person to dry them.

Laundry Separation and Folding

Asking an older adult to help you folding the laundry is a great way to keep them busy, give them an activity they can feel accomplished, and help them feeling like they're contributing to the household.

Materials: Basket with assorted laundry for folding

Application: Sorting and folding the laundry are a necessary task in preparation for ironing. Place face cloth or towel, children's shirt and pants, boxer shorts, nightgown, pillowcase and sheet in front of the patient. It is best to use hand towels as they are small and fold easily. It is not very important that the laundry he/she folded is neat. The aim is just to keep them happily occupied. No matter how well or poorly folded the towels are, the point is, your older adult feels good about the activity. Do not interfere. Do these things together [3,6].

Sock Pairing

Materials: Put the socks in front of your patient.

Application: Pair together. Do not interfere, although **sometimes** he/she can also match non-pairs. The important thing is that you spend pleasant moments with your patient [7].

House Sweeping, Dusting, and Mopping

Materials and Application: Give your patient a vacuum cleaner. Ask him/her to vacuum the parts of the house that can be easily vacuumed. Give your patient a duster. Guide him/her to dust some parts of the house. In the same way, give your patient a mop and ask him/her to mop the relevant parts of the house [8].

Sorting Forks, Knives, and Spoons

Materials: Cutlery tray, cutlery, small bowl, or basket

Application: Put the cutlery in the small bowl and place it on the table with the cutlery tray. Put a knife, spoon, and fork in the appropriate place on the tray and ask the participant to separate the cutlery from the bowl to the tray [3].

Polishing

Materials: Silver cutlery for 4 people, small tube of toothpaste, cloth for applying "polish", soft cloth for polishing.

Application: Put the silver, toothpaste, and cloths on the table. Show it off by putting a small amount of toothpaste on the cloth, cleaning a piece of cutlery, and then buffing with a soft cloth. Ask the person to polish any remaining silver. Shoeshine is also a good "polishing" activity [3].

Making Tea or Coffee

Try using written instructions to help them if the problem seems to be that the person has difficulty with the steps involved in doing something. For instance, if they have trouble getting a cup of coffee even after finding a cup, post instructions like:

Application: You can give a written instruction for this. Take the cup. Get the pitcher. Fill your coffee cup. Add sugar and milk and mix. You may need to add more steps such as “Get milk from the fridge” and “Open the coffee pitcher”. Use as few steps in the instructions as necessary to ensure they can successfully complete the task. Things like using the remote control, doing the laundry, making a pot of coffee are all examples of things that can be done with the right written instructions [3].

Cooking

For cooking, let your patient cook simple meals that they previously enjoyed cooking. Put the ingredients in front of the patient in the appropriate order, depending on which of the dishes he/she wants to cook. When necessary, you can give detailed instructions on which of the food ingredients and when to cut, add oil, and cook. Early-stage patients are capable of doing these without proper instruction. However, they may need little help in the middle stage. You can also ask for help in sorting and cutting the materials necessary for the meal while you cook. Someone who loves to cook may enjoy measuring spoons, whisks, spatulas, and other related items.

It can work for any type of business or hobby, just get creative with finding objects that will be safe to use [9,10].

10.3. Other Indoor Activities

Separation

Materials: 6 or more colored latches in a bowl, a small bowl, or container that approximately matches the colors of the latches.

Application: Place the latch bowl on the table with the empty, colored bowls. Take a latch and attach it to the rim of the corresponding-colored bowl, then ask the person to separate the remaining latches. If they can’t tighten the latches to fasten the sides, ask them to put it in the appropriate bowl. Our “Match Pins” includes everything needed for various latches sorting [3].

Sorting coins of different values into bowls is another good sorting activity.

Painting

Self-expression helps elder feeling good, and painting is a soothing activity that allows them to express their feelings.

Materials: In order to keep this activity simple, try choosing washable and non-toxic art materials like tempera paints.

Application: You can put your loved one near a window so you can see the view or encourage him/her to make abstract strokes on the paper [11].

Watching Family Videos

Your loved one can also enjoy watching videos whenever they need a quiet activity. Family videos preserve memories and your loved one may even recognize some people on the screen. Keep in mind! If the events in the movies cause confusion, you shouldn't force your loved ones to remember. Instead, let him/her watch the movies. You never know when something will trigger a memory [11].

Vision Board Construction

Vision boards are easy to make and can provide insight into what your loved ones love. A vision board is a collage that people use to reinforce their goals, but your loved one can fill the board with images of things that appeal to them.

Materials: Get a piece of poster board and blunt scissors.

Application: Your loved one can cut pictures from magazines and paste them on the board. This activity can take several days to complete and your loved one will have a fun piece of art to display when finished [9,11,12].

Create a Memory Box

Creating a memory box can help your elder feel connected to their past careers and previous hobbies.

Materials and Application: For instance, create a box for a former office worker that reminds him/her of his/her career. It can be a shoebox. Add paper clips, pencils, erasers, papers, letters, calculators, file folders, notepads, etc. to the box. Take the box and fill it with things they will use at work, photocopies, and trivial memorabilia or objects from hobbies. In case that the person has been doing crafts before, put nuts, bolts, pieces of PVC pipe and fittings, a piece of wood (no splinters), fine sandpaper and twine in the box. Someone who loves to cook may enjoy measuring spoons, whisks, spatulas, and other related items. It can work for any type of business or hobby, just get creative with finding objects that will be safe to use [13].

Untie the Knots

Materials: Medium-thick yarn or string

Application: Loosely tie a few simple knots and ask your elder to help you untying them [13].

Passing Pasta Though Yarn or String

Materials: Take some dry pasta with large holes and some thick yarn or regular yarn. Tape the end of the string to make a "needle" and make it longer than the piece of pasta.

Application: Have your elder string the pasta using his "needle" and yarn [13].

Create a Box of Fun Fabric

It's fun for everyone, but especially for someone who used to enjoy sewing or fabric work.

Materials: Take a box and put dozens of different types of fabric in it. Try to get different colors and various textures like lace, felt, silk, velvet, wool, cotton etc.

Application: Your elder can enjoy touching, folding, and separating fabrics [13].

Cutting and Pasting Pictures

Cutting pictures from magazines is a great activity for people with dementia. Older adults may like to shuffle through old magazines or calendars and cut out pictures they like. It's best to use magazines that reflect their hobbies or interests. For those who want to have fun, they can create a fun "scrapbook" by pasting pictures into a notebook.

Materials: Pictures from old magazines or calendars, glue and notebook

Application: You can ask him/her to paste the pictures he/she cut into another notebook [14].

Kneading the Dough

For early and middle stage patients

Materials and application: A bowl full of flour, a glass full of water, a medium-sized dough kneading bowl (If you plan to make foods such as bread and cookies with this dough, put other necessary materials in front of the patient). Ask your patient to make dough. With the dough, you can also make shapes for the foods you will cook later, together with your patient [15].

Button Sewing

It is suitable for early, intermediate, and advanced stage patients.

Materials: A large piece of cloth, large colored buttons, and a medium needle.

Application: Ask your patient to sew these buttons to the cloth with a needle. While early-stage patients don't need any help, you can show intermediate and advanced patients how it's done [8].

Knitting

For early and middle stage patients:

In case that your patient knows how to knit before, you may not need to give instructions, especially to early-stage patients. However, you can provide some help to patients in the middle stage. Since knitting is an advanced habit, most patients will be able to knit with this habit. The knitting does not have to be very good. Therefore, do not interfere in making it better [15].

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CHAPTER 11

WHAT PHYSICAL ACTIVITIES CAN WE DO?

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Chapter Content

11.1. Introduction

In this section, information will be given regarding what reliable physical exercises are for the elderly and Alzheimer's patients, the benefits of these exercises and how long we should do them.

There is no cure or vaccine for the disease yet. However, there are some precautions to be taken in terms of slowing down the disease and increasing the quality of life of the patient. Exercise comes first among the measures to be taken. In many studies conducted to date, results have been obtained that physical exercise can reduce or delay the occurrence of the disease [1]. Effective studies have shown that even light physical activity reduces the risk of cognitive impairment later in life. Studies conducted recently suggest that sedentary behavior, such as watching television for at least four hours a day, in young adulthood, weakens memory in middle age.

On the other hand, physical exercise also prevents the formation of dementia and chronic diseases in elder people. One of the cases that reduces the quality of life of the patient is the difficulties he/she will experience in maintaining his/her social life freely. One of the most important factors that prevent patients from moving freely is limitation of movement. Restriction of movement negatively affects the relationship of the individual both emotionally and socially. Another problem that the patient will experience due to the limitation of movement is the mental and physical problems of the individual. The patient, who is inactive for a long time, already weakens in the muscles due to age. The combination of social, mental, and physical stimulation is the best medicine for a healthy life. Even after he/she has been diagnosed with Alzheimer's, you should continue enjoying activities and replace them as needed. Regular exercise can help you better cope with the negative effects of this disorder [2].

As a result, physical activities are important to slow down the loss of previous learning, which is the biggest difficulty of the patient's daily life and forgetting that prevents him/her from fulfilling the needs of daily life.

11.2. Benefits of Physical Activities

The benefits of exercise in Alzheimer's patients may apply even to those at highest risk of developing the disease according to scientists working on the subject.

Some reliable sources have found that exercise reduces the risk of developing Alzheimer’s disease. It supports recommendations from past studies that exercise has beneficial effects, including slowing the rate of cognitive decline in healthy people, those at risk for dementia, and those who already have it [3,4].

- **It delays cognitive decline.** Even after cognitive loss has begun, physical activity can delay further loss. It showed that among older adults with memory complaints, those who did physical exercise (moderate physical exercise) had a significant improvement in measures of cognitive impairment compared to those who did not exercise. Even after the exercise program ended, the gains continued for another year and a half [2].
- Cardiovascular health of individuals who exercise is better.

It increases heart rate and breathing over a long period of time. It is to reduce the decrease in performance of the small blood vessels to the brain and increase the more efficient pumping of oxygen throughout the body. It is also important for brain health. Dr. Baker, director of scientific studies at the American Alzheimer’s Association, said he has some evidence that healthy blood pressure and good cardiovascular health benefit the brain. According to him/her, exercise enables persons to fight dementia by increasing the number of synapse connections in the individual’s brain, improving cell walls, and vascular health in order to provide better nutrient exchange [2,3,5,6,9,10].

- It helps regulate blood pressure and lowers blood fat levels. It can positively affect the risks of diseases that affect both the heart and the brain.
- It regulates metabolism. When insulin sensitivity is maintained, it can reduce the likelihood of developing diabetes.
- Exercise also reduces inflammatory responses in the body. It is known from recent study that inflammation paves the way for heart disease, rapid aging, depression, and major neurological disorders (a new term that includes what we used to call dementia).
- It protects muscle and bone health. When our muscles get stronger, our bone health is also protected.
- People who exercise participate more in social life. They meet people with whom they will make new friendships. Individuals with more social life feel better both spiritually and cognitively.
- It prevents the weight that prepares the ground for many diseases.

- It helps reducing anxiety.
- It makes the individual to be more energetic,
- It fixes sleep problems
- It is good for circulation problems.
- It makes the individual more resilient.
- It helps prevent constipation.
- It enables the hands, feet, and other parts of the body, which are called motor skills, to be used effectively.
- It creates a calming effect on the individual.
- It increases the emotional bond with the person with whom he/she is exercising.
- It reduces the symptoms of depression.
- It reduces the risk of high falls and fractures in Alzheimer's patients who exercise.
- It reduces low quality of life.

11.3. Which Exercises, How, and How Much We Should Do?

Below are some examples of the types of exercise a person can do. This is by no means an exhaustive list - any form of exercise can benefit. Since exercise can greatly benefit adults diagnosed with Alzheimer's, it is important that your loved one does this type of exercise safely.

11.3.1. Safe Exercises for Alzheimer's

Walking

Walking outside with a loved one or on a supervised treadmill for 30-45 minutes each day can produce the desired effect. If continuous exercise is difficult at first, you can break up the walk into mini sessions.

Walking is an activity suitable for everyone. It's free, requires no special equipment, and can be done anywhere. The distance and time spent walking can be changed according to fitness levels. You can join group walks of various distances, organized by some local entertainment centers and other organizations, and sponsored by a walk leader. Such walking activities also increase social bonds.

Chair exercises

Chair exercises work a variety of muscles. Below are some muscles you can strengthen and develop during chair exercises [7].

- **Strengthen your shoulders with the shoulder press.** Sit in a chair with feet hip-width apart, bend your elbows, and place your hands on your shoulders. Press your arms towards the sky. Repeat 8-12 times. Focus on pressing your arms straight up into the sky over your shoulder. Not in front or behind your body.
- **Strengthening the abdominal muscles with crunches.** You can strengthen these abdominal muscles without lying on the floor. Sit in the middle of a chair with your feet hip-width apart and cross your arms in front of you. Lean back on the chair and straighten your torso, keeping feet and knees apart. Then, in a controlled movement, lean forward and then lean back into the chair. Repeat this move 8-12 times.
- **Flexing your toes.** When we wear tight shoes or socks all day, it can sometimes be helpful to flex our toes. Put a small towel under one of your feet. Sit back in your chair and stand up straight. Place your feet on the floor on the towel. As with our other exercises, keep your knees hip-width apart. Curl your toes as you try to squish the towel under your feet. Imagine pulling it towards you, curling your fingers as close as you can. After collecting most of the towel under your first foot, switch to the other foot by placing your towel under it. Repeat 3 times for each foot.
- **Strengthening movement of arm, elbow, and wrist** (Biceps curl). Sit in your chair with your feet flat on the floor and put your arms at your side. Slowly raise your arms towards your shoulders and keep your elbows at your sides. Keeping your wrists straight and the 90-degree angle at your side, lower your hands in a controlled and steady motion. These movements help building strength in our arms, so we feel more confident when picking up items or balancing ourselves in case of a fall. You can also use a 1- or 1.5-liter water bottle while doing this exercise.
- **Stretch your calves.** Stretching your calves can help improve balance and coordination. If you don’t walk often or do a lot of cardio (like jogging, swimming), strengthening your calves can

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help you feel better in other parts of your body. Lift your heels up while keeping your toes on the ground. Hold this position for 2 seconds. Return your heels to the starting position. Repeat 8-12 times [11].

Other Moves

- **Riding a stationary bike**. Simple and repetitive movements are ideal for people living with Alzheimer's. Riding a stationary bike will contribute to your heartbeat and muscle movement in addition to ease of movement.
- **Weightlifting**. Weightlifting is an important exercise that should be incorporated into a regular routine as you age to combat bone loss. It has also been associated with cognitive improvements in several studies with older adults. Alzheimer's patients should only lift weights under the supervision of a supervisor [8]. You can use pet bottles filled with water for weight.
- **Gardening**. Gardening is a physical activity that provides an opportunity to get outside and is enjoyed by many. The activity level can be changed to suit one's abilities. There may be activities that require less effort, such as weeding or pruning, and more strenuous activities such as mowing or raking the lawn. These activities can help strengthening the body's muscles and improve breathing. Gardening can be an enjoyable activity for people of all stages of dementia.
- **Dance.** Dances with improvisational movements can be performed in pairs or in groups. It can also be done in a dancing and sitting position. It is a very social activity and a fun way to get involved in exercise. It can increase strength and flexibility, help staying stable and agile, and reduce stress.
- **Sitting exercises.** People with dementia can benefit from exercise sessions by sitting regularly with a group at home or at a local classroom. It is generally a good idea to see these exercises demonstrated at least once by an instructor or in a video. These exercises are aimed at building or maintaining muscle strength and balance and are less strenuous than standing exercises. They can be part of a program that evolves with the number of repetitions of each exercise increasing over time. Here are some examples of sitting exercises:
  - Turning the upper body from side to side
  - Elevating heels and toes

  - Raising arms towards ceiling
  - Raising the opposite arm and leg
  - Bending the legs
  - Making circles with arms
  - Practice from sitting to standing.

- **Swimming**. Supervised swimming is a good activity for people with dementia. Many people find the feeling of being in the water soothing and calming. Some studies have also demonstrated that swimming can improve balance and reduce the risk of falls in the elderly.

11.4. Exercise Prescription

The US government has established a program (FITT) to define appropriate exercises for individuals with Alzheimer's, the frequency, intensity, time, and type of exercise. This model includes exercises and guidelines that can be used as a guide for individuals with Alzheimer's. Let's look at each of these components.

Frequency of Exercises

Aerobic activities can be done most days of the week. Muscle-strengthening activities should be done at least two days a week. Elders can achieve these goals gradually. It is important that the activity can start a day or two in the first week and individuals gradually reach the level to be done every day over a few weeks.

Intensity of Exercise

Exercise should be carried out at a moderate intensity level. Any activity that requires an effort, such as brisk walking or raking in the garden, qualifies as moderate intensity.

Duration of Exercise

It is advised to do aerobic activities for at least 150 minutes per week. Also, muscle-strengthening activities should be done two days a week.

Type of Exercises

Guidelines recommend individuals engage in both aerobic and muscle-strengthening activities. They also have specific recommendations for elders, which is especially important for individuals with Alzheimer's, as many will fall into this category. It states that "elder should engage in multicomponent physical activity as part of their weekly physical activity, which includes balance training as well as aerobic and muscle-strengthening activities." Indeed, many exercise studies involving individuals with Alzheimer's must be conducted in a multi-component program that combines aerobic, strength, balance, and flexibility activities into a single program.

When selecting types of activities, it is important to choose those that are enjoyable and sustainable. This process may take some time but doing the exercises routinely and finding our own routine leads to long-term success. Maintaining a regular exercise program is important since the benefits of any exercise program are lost once you stop exercising. Below are examples of these different types of activities.

Aerobic activities: Brisk walking, water aerobics, dancing, gardening, biking for 10 miles, doing yoga.

- **Muscle strengthening activities:** Use of exercise bands, hand-held weights or weight machines, bodyweight exercises (e.g., push-ups), and types of yoga.
- **Balance:** Standing on one foot, walking on heel-toe, lifting toes.

It is also important to warm up before exercise and cool down after exercise. Warming up helps preparing the heart and lungs for activity and cooling down helps gradually slowing the heart and lungs. Stretching may also be involved in warming up and cooling down. It helps maintain the flexibility of the joints.

11.5. Additional Exercises for Older Adults

Elders should consult their physician before starting any exercise program. National guidelines also provide measures for elders to engage in activity relative to their fitness level and to measure the extent to which chronic health conditions can affect ability of a person to be active. Elders should be encouraged to participate in at least 150 minutes of activity per week. Individuals with Alzheimer's should strive to achieve specified activity levels, taking into account their current physical health.

An Exercise Program

Exercise programs offer a wide variety of exercises, including aerobics, strength/endurance (resistance), and flexibility (stretching) exercises. Each session consists of warm-up, aerobic, resistance, cool-down, and stretching phases.

Warm-up Phase

It consists of light to moderate intensity aerobic activities for 5-10 minutes. At this stage, treadmill and/or stationary cycling or walking/running activities are used to activate the largest muscle groups.

- **Move 1.** Performing aerobic movements lasting 15-20 min with treadmill, stationary bike, and/or jogging. The duration and intensity of this exercise should be done at light to moderate intensity for a maximum of 12-13 minutes. It starts with two minutes at the beginning, these movements that are done intermittently are continued until the level that can be done continuously for 10 minutes is reached in the future. It can also be extended to 16-17 minutes for time.
- **Move 2.** Then, the resistance phase starts, which lasts 20-25 minutes and includes the main muscle groups, body limbs, and body. At this stage, bodyweight exercises are performed. For this, push-ups and 2 kg dumbbell lifting can be done. These movements can be progressed to 2 series of 10 repetitions for each muscle group, up to 20 rapid repetitions up to 6 series.
- **Move 3.** Finally, the stretching phase, which takes less than 10 minutes, consists of flexibility exercises for each major muscle/tendon group. Participants can stretch to the point where they feel tension or mild discomfort, do a static stretch for 20-30 seconds, and repeat the exercise 2-3 times for each muscle/tendon group (*13*).

11.6. What is the Best Exercise?

In summary, there are many different exercises that are suitable and safe for individuals with Alzheimer's. It's important to participate in several different categories of exercise, including aerobics, muscle strengthening, balance, and flexibility. Therefore, the answer to the question "What is the best exercise for individuals with Alzheimer's" is that all exercises are safe, enjoyable, and sustainable [2].

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CHAPTER 12

PROBLEMS OF CAREGIVERS

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Chapter Content

12.1. Introduction
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12.1. Introduction

Alzheimer’s is a neurodegenerative disease that manifests itself with cognitive and physical losses of the individual. Today, there is no treatment that will prevent or stop the progression of the disease. However, it has not reached the treatment stage although there are some trial studies for the prevention and stopping of Alzheimer’s. In the first stage of Alzheimer’s, the patient starts to become a disabled individual later while it manifests itself with forgetting. Therefore, it causes caregivers to take more responsibility. Family members bear the greatest burden of caring for Alzheimer’s patients. The families of patients are forced to become more and more responsible. Therefore, it is very important to reduce the negative consequences of the patient’s family members from long-term care.

12.2. Possible Problems Experienced by Caregivers

Studies have demonstrated that caring for a family member with Alzheimer’s can have serious adverse effects, including fatigue, depression, anxiety, poor immune function, and physical illness. For caregivers who are wives or husbands of Alzheimer’s patients, the disease is a particularly heavy responsibility. Many caregivers are elderly and suffer from chronic diseases, many of which become more common with increasing age. They find themselves providing care to the person who was the mainstay of their social support before they got sick [1].

12.3. Emotional Problems

11.3.1. Depression

Many caregivers experience depression. If you experience symptoms, know that you are not alone, and that help can be overcome. Depression is a serious condition, but it can be treated.

Depression Symptoms

Caring is difficult and can lead to feelings of stress, guilt, anger, sadness, isolation, and depression. Depression affects different people in different ways and at different times. For instance, a person may experience depression soon after their family member is diagnosed with Alzheimer’s. Other caregivers may experience this problem as Alzheimer’s progresses and the cognitive abilities of the person with Alzheimer’s decline. Depression signs and symptoms include [2]:

- Getting angry or frustrated easily

- Feelings of worthless or guilty
- Feelings of hopelessness
- Thoughts of death, dying, or suicide
- Sleeping discomfortably
- Fatigue or loss of energy
- Loss of interest or pleasure in usual activities
- Difficulty thinking or concentrating
- Appetite and weight changes
- Physical symptoms which are unresponsive to treatment, such as headache, digestive disorders, and pain (American Psychiatric Association Diagnostic and Statistical Manual of Mental Disorders).

Coping with Depression

If you are worried that you may be depressed, see your physician as soon as possible. Some medications and certain medical conditions can cause the same symptoms as depression. A physician can rule out these possibilities by performing a medical examinations and laboratory tests. If depression is left untreated, it can lead to emotional and physical problems. It can also affect the quality of care you can provide to someone with Alzheimer's or dementia.

If you see a physician for treatment, he can give you two types of treatment. One of them is medication. The other is to get counseling help. Sometimes both methods can be applied together.

Medications. If you use various antidepressants prescribed by the physicians, your mood will improve. Do not decide for yourself whether to take the drugs your physician has given you. Act in accordance with your physician's recommendations for using medications.

Consultancy. Your physician may refer you to a mental health professional, such as a counselor, psychologist, psychiatrist, or social worker. Counseling can be very effective in treating depression and can help you coping with the problems you are facing. It is important that you are comfortable with the professional you are treating, so consider meeting with the counselor for a good fit.

Other Ways of Coping with Depression

Besides seeking help from a professional, you can take steps to help yourself [2].

- Let your family and friends help you. Accept other people's offers of help and ask for help when you need it.
- Look for caregiver support. Seek help from a caregiver if you can. You can get full-time or hourly caregiver assistance from local Alzheimer's associations, municipalities, and social service agencies. Also, you can leave your patient to these centers at certain times if there are day care centers in your area.
- Keeping in touch with recreation services, a local caregiver support group, or online communities, if any, can be comforting. It is especially comforting to talk to people who have similar problems. It also allows you to benefit from the different experiences of each caregiver. Building a support network can keep you from feeling isolated.
- Try keeping a diary. Expressing your emotions (both negative and positive) in a diary can boost your mood.
- Learn ways to relax and manage stress. Try meditation or yoga to help reduce caregiver stress.
- Take time for yourself. Participate in activities you enjoy.

12.3.2. Anxiety and Stress

Alzheimer's caregivers often report experiencing high levels of stress. Caring for a loved one with Alzheimer's or other dementia can be overwhelming, but too much stress can be harmful to both of you [3].

Signs of Caregivers' Stress

- Denying about the disease and its effect on the person diagnosed. For example, "*I know my mother will get well*".
- Don't get angry or frustrated at the person with Alzheimer's at not being able to do things they used to be able to do. For example, "*He/she knows how to dress - he/she's just stubborn*".
- Social distancing from friends and feel-good activities. For example, "*I don't care about visiting neighbors anymore*".
- Worrying about the future and facing another troubled day. For example, "*Can I handle all this work today?*".
- Depression that breaks your spirit and affects your ability to cope. For example, "*I don't care about anything anymore*".
- Feeling exhausted that makes it nearly impossible to complete necessary daily tasks. For example, "*I am too tired for this*".

- Insomnia due to never-ending worries. For example, "*What if he/she runs out of the house or falls and hurts himself/herself?*"
- Irritability that leads to pessimism and triggers negative reactions and actions. For example, "*Enough is enough, leave me alone!*"
- A lack of attention that makes it difficult to perform familiar tasks. For example, "*I was so busy, I forgot my appointment*".
- Feeling unwell due to mental and physical responsibilities. For example, "*I can't remember the last time I felt good*".

If you regularly experience any of these stress symptoms, take time to talk to your physician.

Tips for Managing Stress

- Get help and find support.
- Search the Internet and local communities for patient care and coping with the emotional states you experience.
- In case that you regularly experience symptoms of stress, consult your physician. Ignoring the symptoms can deteriorate your physical and mental health.
- You can search local Alzheimer's associations, social services, and the Internet for services that can help you manage daily tasks.

Use Relaxation Techniques

There are several simple relaxation techniques that can help relieve stress. Try more than one of them to find which one suits you best.

- Visualization (mentally imagining a peaceful place or situation)
- Meditation (we can take 15 minutes a day to get rid of all stressful thoughts).
- Breathing exercises (slowing your breathing and focusing on deep breathing)
- Progressive muscle relaxation (tighten and then relax each muscle group, starting at one end of your body and working your way to the other end)

Do Physical Activity

Physical activity - in any form - can help reducing stress and improving your overall well-being. Even 10 minutes of exercise a day can help. No doubt, you know that exercise is an important part of staying healthy – it can help relieving stress, preventing illness, and feeling good. However, finding time to exercise can be another problem. Get help from your friends and family members, even for a short time.

While it is recommended to do 30 minutes of physical activity at least five days a week, even 10 minutes a day can help. Do your best and work towards a goal. Find something you love and do it. If you enjoy the activity, it will be easier for you to make it a habit.

Do Activities That You Can Do with Your Patient

There are many ways to be active with the person with dementia. Here are a few ideas:

- Take a walk outside with your patient to enjoy the fresh air
- Go to the mall and take a stroll inside
- Exercise sitting at home
- Dance with your favorite music
- Do the garden or other routine activities that you both enjoy
- Activities you can do yourself
- Take a walk alone or with a friend.
- Do gardening
- Dance
- Exercise at home. When the person with dementia takes a nap, pull out a yoga mat and stretch, set up a stationary bike, or try exercise bands.
- Do Tai-Chi.

Pay attention to your diet. Heart-healthy dietary patterns, such as the Mediterranean diet, are good for general health and may help protect the brain. The Mediterranean diet contains relatively less red meat and emphasizes whole grains, fruits, vegetables, fish, nuts, olive oil, and other healthy fats. Try new recipes and include the person with dementia in this nutritional diet.

Other Rope Tips to Help You Deal with Stress

Manage your stress level. Stress can cause physical problems (blurred vision, stomach irritation, high blood pressure) and behavioral changes (irritability, lack of concentration, change in appetite). Note your symptoms and see a physician as needed. Try to find relaxation techniques that work for you.

Be realistic. Your care makes a difference, but many behaviors cannot be controlled. Focus on the positive times and savior the good memories as they arise.

Remember that the care you provide makes the difference and you do your best. You may feel guilty for not being able to do more, but individual care needs to change as Alzheimer's progresses. You can't promise how care will be provided, but you can rest assured that the person with the disease is well cared for and safe.

Take a break. It is normal for you to take breaks from maintenance tasks. No one can do everything by himself/herself. You should consider respite care to give yourself time.

Accept changes as they happen. People with Alzheimer's change over time, and so do their needs. They may need care beyond what you can provide on your own. Being aware of community resources and care options, from home care services to home care, can facilitate the transition. Get support and help from those around you [3].

Become a trained caregiver. As the disease progresses, new care skills may be necessary. The Alzheimer's Association offers programs to help you better understand and cope with the behavioral and personality changes that often accompany Alzheimer's. You may also find it helpful to talk to other care partners and caregivers regarding how they are coping with the challenges of the illness and uncertainties related to the future.

Read local and national Alzheimer's association print and online books to help family members of someone with amnesia regain control of their lives.

There are many videos available online to help your patient and you. **Watch these videos.** These videos give you practical **care skills to help you** becoming a confident caregiver and reducing your stress.

Take care of yourself. Visit your physician regularly. Try to eat well, exercise, and get plenty of rest. Being healthy can also help you become a better caregiver.

Make legal and financial plans. As your partner's memory decreases, you may find yourself taking on a new role in your relationship. A person with Alzheimer's may no longer be able to perform certain tasks, such as paying taxes, dealing with financial and legal affairs, and doing some household chores. Making important decisions on your own can be overwhelming.

Be prepared for these changes. Find financial and legal documents such as life insurance policies, property titles, and retirement accounts right after your loved one is diagnosed. Consult family, friends, professionals, or community resources for help as needed.

Having future plans in place can provide comfort to the whole family. Many documents can be prepared without the assistance of a lawyer. However, if you are unsure of how to complete legal documents or make financial plans, you can seek help from a lawyer and a financier who specializes in old age law.

See the physician. Make sure you visit your physician regularly (at least once a year) and listen to what your body is telling you. Take seriously any fatigue, stress, insomnia, loss of appetite, or changes in your behavior. Ignoring these symptoms can deteriorate your physical and mental health [1,4].

Focus on Changes in Your Relationship. As the disease progresses, your relationship with your spouse or partner with Alzheimer's will change. But your connection can still be rich and satisfying. Spend time together in ways that bring you closer and help you build relationships.

Experiencing privacy issues. You may be feeling great grief over the changes in your relationship. You are not selfish for having these feelings. Considering your partner's cognitive decline, you may no longer have the same emotional or physical intimacy you once shared. It is typical for people with Alzheimer's to experience changes in their sex drive. Depression can cause decreased interest in sex, as well as physical illness and certain medications. It is also common for caregivers to lose sexual desire due to changes in their partner's personality due to caregiving demands, transition from intimate partner to caregiver, and progression of dementia. Don't feel guilty if your sexual attraction to your partner has changed. You can find new ways to connect with each other.

Spend more time with family and friends. You may feel socially isolated because your family and friends have withdrawn from your relationship, or you have little time to spend with them. Your family and friends may hesitate to spend time with you and the person with Alzheimer's since they are worried about not knowing what to do or say. They may also not be able to understand the behavioral changes caused by the disease or accept that the person has the disease [5].

Take the initiative to connect with your family and friends and explain that you value their friendship and support even though Alzheimer's disease has changed your life in some ways. Consider inviting a few friends or family members. Let them know in advance if there are any physical or emotional changes in the person with dementia. Make recommendations regarding how to communicate with the person and activities they can do together.

12.4. Relaxation Techniques

There are many treatment options for your anxiety and stress, but one of the best things you can do to manage your stress is to get relaxed. Below are some relaxations and breathing techniques. Applying them regularly can help us relax. Relaxation skills relieve anxiety for the body by reducing muscle tension, slowing breathing, and calming the mind. Below are six relaxation techniques that can help you reducing stress:

1. Breath focus. In this simple and powerful technique, you take long, slow, and deep breaths (also known as belly or belly breathing). As you breathe, you gently clear your mind of distracting thoughts and feelings. However, this technique may not be suitable for those with respiratory conditions or health conditions that make it difficult to breathe, such as heart failure.

2. Body scan. This technique blends a focus on the breath with progressive muscle relaxation. After a few minutes of deep breathing, you focus on one part of the body or muscle group at the same time and mentally release any physical tension you feel there. A body scan can help increasing your awareness of the mind-body connection. If you have recently had surgery that affects your body image or have had other difficulties with your body image, this technique may be less helpful for you.

3. Guided images. For this technique, you create relaxing scenes, places, or experiences in your mind to help you relaxing and focusing. You can find free applications and online recordings of soothing scenes. Be sure to choose only images that you find comforting and that have personal significance. Guided imagery can help you reinforcing a positive vision of yourself, but it can be difficult for those who have intrusive thoughts or find it difficult to form mental images.

4. Awareness meditation. This practice includes sitting comfortably, focusing on your breath, and drawing your mind's attention to the present moment without being dragged into worries about the past or the future. This form of meditation has gained increasing popularity in recent years. Studies suggests it may be beneficial for people suffering from anxiety, depression, and pain.

5. Yoga, tai-chi and qigong. These three ancient arts combine rhythmic breathing with a series of postures or flowing movements. The physical aspects of these practices offer a mental focus that can help distract you from racing thoughts. They can also improve your flexibility and balance. But if you're not normally active, have health problems, or have a painful or disabling condition, these relaxation techniques can be overwhelming. Consult your physician before starting.

6. Repeated prayer. For this technique, you silently repeat a short prayer or phrase from a prayer while you practice focusing on the breath. This method can be particularly appealing if religion or spirituality is meaningful to you.

You can try a few of the above techniques to see which one works best for you. Try to practice for at least 20 minutes a day, but even just a few minutes can help. However, the longer and more often you practice these relaxation techniques, the greater the benefits and the more you can reduce stress [6].

Graduated Relaxation Technique

Below is a practice on how to do a gradual relaxation to help your body relax. While you must read the steps in this application at the beginning, you can memorize it over time.

Choose a comfortable environment for yourself. Beware. Lie down on a carpet or cushion in a room where no one can disturb you for at least 30 minutes.

- Clench your right fist, hold it for a while and relax. Pay attention to how you feel your hand muscles when your hand is clenched and then relaxed.
- Now slowly squeeze the same fist and after a while slowly relax it. Again, keep your attention on your muscles, and observe how the fist changes as it clenches and relaxes.
- Now squeeze your left fist, hold it for a while and relax.
- Squeeze your left fist slowly and after holding it for a while, release it slowly.
- Stretch your biceps by bending both arms at the wrists as if you are lifting a weight, gradually increasing this tension and then leaving it completely relaxed.
- Repeat the previous step slowly.
- Lower your arm, place the back of your hands on your legs, and push your arms back with increasing force. Then relax completely and become aware of the muscles in the back of your arm.
- Now drop your arms to the side of your body and relax them completely and imagine the tension flowing out of your arm.
- Wrinkle and stretch your forehead by raising your eyebrows upwards. Keep it tense for a while, then loosen and release.
- Close your eyelids tightly and hold it for a while. Then, relax your eyelids without opening your eyes. Notice the profound difference between tightness and slack in your eyelids and the muscles around your eyes.
- Tighten your jaw and temple muscles by clenching your teeth. After a while, relax and leave your jaw loosely and your mouth half-open.
- In order to be aware of your neck muscles, throw your head back and stretch the muscles between your neck, then turn

your head to the right and then to the left while your muscles are tense, then lean forward. After holding it tight for a while, loosen it.

- Lift your shoulders up and stretch the muscles between the shoulder and neck, hold it for a while and then relax it completely. Completely relax your shoulders, then your arms, neck, chin, eyelids, and forehead. Imagine the fatigue and tension flowing from top to bottom, from your shoulders to your arms, and then from your fingertips to the floor. Notice that your tension is gradually easing.
- Take deep breaths and notice the tension in your chest. Hold your breath and observe the tension of your chest muscles. Now relax completely by exhaling.
- Now start breathing slowly and regularly. Imagine your body relaxing with each exhale. Keep breathing and observe that the tiredness in other parts of your body gradually disappears as you breathe in.
- Now contract your abdominal muscles and hold them tight for a while. Then relax and notice the big difference between when your abdominal muscles are relaxed and tense.
- Tighten the muscles on both sides of your spinal cord, making sure that these muscles are tense while other parts of the body are relaxed. After holding these muscles, a little tight, relax them and notice the difference between them.
- Keep breathing and relax whatever muscle is tight in your upper or lower body. Keep relaxing until there are no tense muscles in your body.
- Now stretch the muscles of your hips and legs, and after a while relax them. Notice the big difference between these muscles being tense or relaxed.
- Increase the tension in your calf muscles by raising your toes without lifting your heels. Become aware of your muscle tension by wiggling your toes while your muscles are tense. Then, relax your muscles completely and observe the difference.
- Stretch the muscles in the front of the calf bones below the knee by pushing your toes back without lifting your heels. After keeping these muscles tense for a while, relax them and observe the difference between them.
- Now review the whole body and relax all of your muscles from head to toe. Lie on the head, forehead, eyelids, chin, neck, shoulders, arms, chest, abdomen, hips, legs, calves, and feet with the muscles completely relaxed. Continue to breathe prop-

erly. Watch the tension in your muscles drain from your arms and legs. Lie comfortably like this for five or ten minutes.

- You can apply it for 15-20 minutes every day [7].

Breathing Exercises, You Can Try When You're Anxious

If you're feeling breathless due to anxiety, there are breathing techniques you can try to relieve symptoms and start feeling better.

1. Extend your breath: Taking too many deep breaths too quickly can cause hyperventilation. Hyperventilation reduces the amount of oxygen-rich blood flowing to your brain. When we're feeling anxious or stressed, it's easier to breathe a lot and hyperventilate—even if we try to do the opposite.

- Before taking a big, deep breath, try exhaling deeply instead. Exhale all the air from our lungs, then let your lungs do their job by breathing in the air.
- Then, try to spend a little longer exhaling than you inhaled. For example, try inhaling for four seconds, then exhale for six seconds.
- Try doing this for two to five minutes.
- This technique can be done in any position that is comfortable for you, including standing, sitting, or lying down.

2. Abdominal breathing: Breathing from the diaphragm (the muscle just below your lungs) can help reducing the amount of work your body has to do to breathe.

In order to learn how to breathe from the diaphragm:

- For your comfort, lie on the floor or bed with pillows under your head and knees. Or sit in a comfortable chair with your head, neck, and shoulders relaxed and knees bent.
- Then place one hand under your rib cage and one hand over your heart.
- Inhale and exhale through your nose, noticing how or whether your stomach and chest are moving as you inhale.

Can you isolate your breath to draw air deeper into your lungs? What about otherwise? Can you breathe with your chest moving more than your stomach?

In the end, you want your stomach to move instead of your chest as you breathe.

- Practice belly breathing
- Sit or lie down as described above.
- Put one hand on your chest and one hand on your stomach just above your belly button.

- Inhale through your nose, notice your stomach rise. Your chest should remain relatively still.
- Exhale through your mouth by pursing your lips. Try working your stomach muscles to expel air at the end of the breath.
- For this type of breathing to become automatic, you need to practice every day. Try doing the exercise for up to 10 minutes three or four times a day.
- If you haven't used your diaphragm to breathe, you may feel tired at first. It will get easier with practice though.

3. Breath focus: Deep breathing and focus can help reducing anxiety. You can do this technique sitting or lying down in a quiet and comfortable place.

- Notice how it feels when you breathe normally. Mentally scan your body. You may feel a tension in your body that you never noticed.
- Take a slow and deep breath through your nose.
- Notice that your abdomen and upper body expand.
- Exhale in whatever way is most comfortable for you, inhale if you wish.
- Do this for a few minutes, paying attention to the rising and descending of your stomach.
- Choose a word to focus and vocalize as you exhale. Words like “safe” and “calm” can be effective.
- Imagine your breath washing over you like a gentle wave.
- Imagine your breath carrying negative and sad thoughts and energy from you.
- When you are distracted, gently bring your attention back to your breath and words.
- Whenever possible, practice this technique for up to 20 minutes a day.

4. Equal breathing: It means you inhale for as long as you exhale [8].

- You can practice even breathing while sitting or lying down. Whatever position you choose, make sure you are comfortable.
- Shut your eyes and pay attention to the way you normally breathe for several breaths.
- Then, slowly count 1-2-3-4 as you inhale through your nose.
- Exhale for the same four-second count.
- As you inhale and exhale, be mindful of the feelings of fullness and emptiness in your lungs.
- Your second count may change as you continue to inhale evenly. Be sure to keep your inhale and exhale the same.

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CHAPTER 13

TALKING WITH CHILDREN ABOUT THE ELDERLY:
HOW TO TALK TO CHILDREN ABOUT ALZHEIMER'S DISEASE?

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Chapter Content

13.1. Elderly Individuals Through the Eyes of Children

Young children can have quite different attitudes towards older people-old age, depending on their age and their relationship with older individuals. In the studies conducted in the literature on the perception and concept development of young children, the answer was sought to the question of "*How children's attitudes and perceptions towards older adults are shaped?*". According to the existing study results, children's attitudes towards the aging process are generally negative. However, the attitude of children towards older adults in general is positive. Children stated that they noticed the positive and negative aspects of aging in studies and said that they had an appropriate emotional response to all aspects of the aging process and to older individuals. Based on the results of their research, *Marks et.al.* suggest that it is necessary to look beyond the attitudes of children towards older people and the underlying reasons for these attitudes (*Marks, Newman and Onawola, 1985; Newman, Faux, and Larimer, 1997*).

In general, children are positively affected by their interactions with older adults if their relationships with older adults are good. Thus, they do not view the physical signs of aging negatively. But they can react negatively to some unpleasant situations associated with aging.

Today, it is very important to reduce the problems experienced by older people and to enable them to interact and integrate with other individuals of society. There are different applications in this regard. One of them is "*intergenerational solidarity*", which is one of the policies on old age in many countries. Although there are different applications for "*intergenerational solidarity*" due to different cultural characteristics on the basis of countries, the common main purpose in all of them is to ensure the solidarity of all individuals in the society. Especially the "*School-based solidarity model*", among the various models, is an effective model that enables people from different age groups (old, child, young) to come together and bond with each other (*Yıldırım, 2015*).

In the school-based solidarity model, different materials can be offered to children. It can also be used in children's books to tell children about elderly people and the problems experienced by these people, in an educational environment. Children's books serve as a mirror for children to see characters who are similar to them and have similar feelings and experiences to them. Books also allow children to open new windows about the world by looking beyond their immediate surroundings and seeing characters and events that occur in other communities or somewhere else in the world (*Rudman, 1995*). That is why one of the resources that can help educate children about aging and prepare them for a long life in the preschool-primary school years is children's literature. These works can provide children with a holistic view of aging, teach them about aging and the aging process, promote positive attitudes towards aging, and promote positive aging. To summarize, from an early age, children can be offered qualified works of literature that tell about the concept of old age in an appropriate way for the age and development of children (*McGuire, 2016*).

Considering the current situation in children's books describing elderly people, it has been stated that there are inadequacies in terms of the representation of the concept of "*being elderly*". For example, it has been observed that age discrimination is included especially in relation to the concept of "*old age*" in children's books. Situations such as discrimination against the elderly in these books, the absence of an important role of the elderly person in the story, and the fact that they are shown as an insignificant person can negate the perception of the elderly. Because children generally evaluate the elderly as not exciting, expressionless, flat, one-dimensional, unimaginative, uncreative, and boring. In addition, in the books, definitions such as "*old*", "*sad*" and "*poor*" are amongst the top terms that are constantly used to describe older people (*quoted; McGuire, 2003*).

For the reasons mentioned above, character representation and illustrations are important in literary works describing elderly individuals and their lives. Because children will be affected by the illustrations of old characters and expressions about them in books. That is why it is important to take into account the following criteria when writing or choosing a children's book about aging or old age: In these books;

- elderly characters should be portrayed in a non-stereotypical way,
- elderly characters should be shown as valuable and contributing members of society,
- elderly characters should play an important role in the story,
- elderly characters should be shown as independent and active persons in the book (*McGuire, 2003*).

13.2. Explaining the Concept of Illness to Children

Explaining important illnesses to children is a delicate matter. Children are psychologically and socially affected by the illnesses of themselves or their relatives. In this process, when talking to children about illnesses, their developmental characteristics should be taken into account. According to Piaget's theory, children who have not yet

"Funded by the Erasmus+ Program of the European Union. However, European Commission and Turkish National Agency cannot be held responsible for any use which may be made of the information contained therein".

reached the concrete operational stage; have difficulty recognizing that words can have more than one meaning or that some words may sound similar but may be expressed with different pronunciations (i.e., synonyms); so, the choice of words and terms to use when explaining illnesses should be made by considering the characteristics of the child (*Whaley, 1999, Citing from Whitt et al., 1979*).

Again, children's understanding of illness is shaped by awareness of the different categories of beings that exist in the world. Children can make systematic predictions about the beings' susceptibility to illness from the age of 5, based on their own situation (*Buchanan-Barrow, Barrett, & Bati 2003*). If the child or a relative has an illness, the expressions used during the explanations made to them are important. The language used should be suitable for children's developmental characteristics and conceptual levels. Particular attention should be paid to the words selected in the statements made.

Again, the use of figurative language in explaining the Illness to children may be of interest to them. Numerous authors have suggested using analogies, metaphors, or imagery to describe illnesses. For example, *Whitt et.al. (1979)* used phone to explain epilepsy and automobile fuel (gasoline) as a metaphor for diabetes (*citing; Whaley, 1999*). But in general, the issue that needs to be decided when explaining illnesses to children is to determine what children want to know and what they should know about their illnesses. Like adults, children want to understand how the illness will affect and change their lives (*Whaley, 1999*). Therefore, when explaining this to children, the changes that will happen in their lives, what they should pay attention to, should be explained to them using child-friendly expressions.

The British Psychological Society (*British Psychological Society, 2020, html-4*) has explained how to explain illnesses to children by age as follows:

0-3 years old

This age group has a tough time understanding the things they can't see and touch. Therefore, it will be difficult for them to understand what illness means. For this reason, when explaining to children in this age group; complex explanations should not be used, short sentences should be formed and the statements should focus on the present tense, too many details should not be added, playing games with the child should be continued in daily routines. Especially playing games with children, explaining in the natural process (for example, playing games with dolls and explaining using stories) would be appropriate. In cases where you need to make changes in your routine with the child, you should be honest while making a statement, but the explanation should be kept short (*For example, "Your mother is working from home. This means that she will be at home a lot with you instead of going to the office", etc.*).

4-7 years old

Children of this age group focus on their immediate environment, what is happening around them, what will happen later and soon, and how they feel at the moment. Children can blame themselves in the process of illness (for example, "*Grandma is sick because I haven't washed my hands*"). Even if it is difficult for this age group (for example, if a loved one is ill), spending time with them and playing games should be continued, stories should be used if necessary. It is necessary to make sure that the child understands the cause and effect, explanations should be made as much as they need, and this information should be repeated consistently.

7-12 years old

At this age, children are now asking more questions than younger children about the effects of illness on other people or the changes it has made in life. They can be encouraged to express themselves emotionally through activities such as painting, reading stories, and asking questions. When talking with children of this age group, different emotions should be appropriately normalized and conversations on anxiety and feelings should be made. It is necessary to make sure that the explanations given to them are correct and the differences between the conditions should be explained (*British Psychological Society, 2020, Dec-4*).

13.3. Talking to Children About Alzheimer's

Having a serious illness such as Alzheimer's in the family affects the lives of all individuals in the family. For example, caregivers of people with Alzheimer's illness in the city of Chapecó, Santa Catarina stated that they faced difficulties such as the need to learn about the illness, coping with guilt, and coping with pain, addiction, and physical and psychological suffering. In a different study, 2678 adults were randomly selected from people who reported having a family member with Alzheimer's in France, Germany, Poland, Spain, and the United

States, and a telephone survey (landline and mobile phone) was conducted with them. The respondents were asked about their beliefs and expected behavior towards non-Alzheimer's people. Survey results showed that the more the general public interacts with a family member with Alzheimer's, the more they will be concerned about Alzheimer's illness and the more likely they will be to accept that Alzheimer's illness is a deadly illness (*Blendon et al., 2012*).

In today's world, children may have relatives from family members who have Alzheimer's, as well as the likelihood of encountering individuals with Alzheimer's in society in society will increase. In order to tell the children about Alzheimer's, to ensure their solidarity and bonding with the individuals who have Alzheimer's in society, it is necessary to explain the illness to them first. When telling children about Alzheimer's, it is worthwhile to first touch on the concepts of "*memory*" and "*forgetting*".

From an early age, children are able to perceive the concept of "*forgetting*" and "*memory*". For example, children first understand the pre-knowledge components of the words "*remember*" and "*forget*" at the age of about 4 years. For this reason, in accordance with the age and development of children, it is possible to talk about what forgetfulness is due to the concept of "*memory*" and "*forgetting*" (*Lyon and Flavell, 1994*).

Alzheimer's illness (AH) affects the entire family system, including young children. Children may react differently when they hear that one of their family members has AH. Possible reactions of children to Alzheimer's illness can be as follows:

- Jealousy and resentment
- Guilt
- Sadness
- Chaos
- Shame
- Anger and frustration
- Fear
- Introversion
- Complaints of vague physical symptoms
- Poor school performance
- Stopping inviting friends over (*Chicago: Alzheimer's Association; adapted and cited from 1997, Winters, 2003, p.38*).

The following steps can be followed when telling children about Alzheimer's:

Step 1*-To determine the current knowledge of children about the subject*: Before telling the children the details of what is happening, it is worthwhile to find out what they know about the situation or what they believe.

"You've probably noticed..........he's been getting more tired lately and can't do his job as much as he used to. I wonder if you've been thinking about it, and if you'd like to talk about it..."

When explaining the illness to children, it may be helpful to share some basic information, such as changes in the person's appearance, the medications used and the symptoms of the illness, from the side effects of treatment or medication, where the person will be (at home, hospital, nursing home), and why this happens if the person's illness progresses.

Step 2*- Giving them a chance to decide and choose:* Children can often feel that they have no control over the situation when someone close to them has an incurable illness. Providing them with clear information and involving them in some decisions can help them make choices about how to manage the situation. For example, if the person is in a hospital or nursing home, they may be asked if they want to visit the person and for how long.

Step 3*- If the daily routine is going to change*: Order is very important for children. If an illness of a relative is going to cause a change in the child's life, you should try to prepare as much as possible in advance and explain what changes may occur, as this will help children adapt.

Step 4*- Frequent and regular check-ups:* Children should be asked regularly if they have questions about what is happening or if they want to talk about how they feel. In this way, children will feel that they can easily talk about their feelings and thoughts about this topic with an adult (*St. Columba's Hospice Care, 2020, html-5*).

As mentioned earlier, children's books can be used in this process. However, there are very few resources available to help children understand AH. In books, AH should not be described with words that children do not understand and are complex in their narration. Again, uncomplicated information about AH should be given in books. It should provide a comprehensive description of the cognitive, behavioral, emotional and functional symptoms of the illness in the stories telling about AH. The prevalence of illness symptoms displayed by storybook characters, and reports of adverse illness progression, vary considerably. For this reason, books designed to inform children about AH should be comprehensive and accurate (*Sakai, Carpenter, Rieger (2012))*. Although the available resources are useful, such books can be written to give health literacy about AH in young children. For example, the book "***Memory Puzzle***" developed within the framework of the ***REMEM Project***, aimed to raise awareness of AH illness for preschool-aged children.

13.4. Conclusions and Recommendations

It is necessary to raise awareness of children about Alzheimer's, to provide information and to ensure that they develop a positive attitude towards individuals with Alzheimer's illness. Briefly, children can be given explanations about this as follows:

Answer children's questions simply and honestly. For example, you might say to a preschooler: *"Grandma has an illness that makes it difficult to remember things."*. This can be said to the school age child*: "Alzheimer's is an illness that causes brain changes. Your grandfather's brain is changing. Sometimes these feelings make him feel confused (or scared or angry). Sometimes these feelings cause him to do or say things he doesn't mean. It's Alzheimer's. It's not your fault."*. During adolescence, an individual may have difficulty accepting how a person has changed. Feelings of shame or discomfort are common. They can also have worries such as "*Will you get Alzheimer's, too? Will I?*" This explanation can be made to them: "*The truth is that Alzheimer's is not contagious. Most people don't get Alzheimer's".*

- Children can be helped to know that their feelings of sadness and anger are normal.
- By comforting them, it can be said to them that the illness is not the fault of anyone (*Alzheimer's Illness Resource Agency of Alaska, html-2*).

Individuals in their teens may find it difficult to accept how the person with Alzheimer's illness has changed. They may find the changes sad or embarrassing and may not want to be around the person. This age group should not be forced to spend time with a person with Alzheimer's illness. This could make things worse. It is important to show children and teenagers that they can still talk to a person with Alzheimer's illness and help them enjoy activities. Doing fun activities together (simple arts and crafts, playing instruments and singing, looking at photo albums together, reading and telling stories together) can help both the children and teenagers, and the person who has Alzheimer's illness (*Alzheimer's caregiving tips-html-1*).

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CHAPTER 14

USE OF THE INTERNET AND MOBILE APPLICATIONS

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Chapter Content

14.1. Introduction

Communication difficulties are common in people with dementia. However, effective communication improves the quality of life of people with dementia. An early sign that a person's ability to communicate is compromised by dementia is the inability to find the right words, especially object names. The person may replace a wrong word or find no words at all. As the disease progresses, communication difficulties become more and more severe, eventually leading to a complete inability to communicate. Behavioral symptoms of dementia, which may include depression, aggression, anxiety, and sleep difficulties, may be accentuated by this loss of communication.

Meaningful communication initiatives using technology and the Internet can help alleviate these symptoms and perhaps reduce their severity. About 30 percent of people with dementia may experience delusions. This shift in perception can be particularly troubling for both patients and caregivers. Having the patient reorient the memory using technology such as showing pictures, YouTube clips of familiar television shows, etc., can help calming a patient who is frightened and overwhelmed by confusion [1].

14.2. Benefits of Internet and Mobile Applications

Technology can contribute to the happiness of the elderly who are healthy or have health problems. In this context, social networks, video calls and games offer very good solutions. Elders are happy when they see the pictures of their grandchildren through the social media site. Having the opportunity to see and talk to their children, who are far from the Internet, via video calls makes elders very happy [2].

For this reason, Alzheimer's patients should use the Internet to do the things they liked to do before or to find new applications that will motivate them. Face-to-face meetings with relatives and people they know through the Internet can ensure that the faces are not forgotten.

Listening to the songs of their favorite artists and watching their movies can take them to one of their own memories. They should use the Internet and technology to motivate themselves or to do memory exercises.

The use of mind games and other computer-based simulation therapy can shed new light on healthcare professionals, caregivers, and patients themselves.

The Role of Innovative Technologies: Innovative technologies such as technologies used to adapt caregiving environments for the cognitive impairment of individuals with dementia or tele-care used to support individuals suffering from dementia and their caregivers can facilitate dementia care. Also;

- Promoting independence and autonomy
- Improving the self-confidence and quality of life of the individual suffering from dementia
- Helping manage potential risks in and around the home
- Supporting people with dementia to live longer in their own home
- Helping memory and recall
- Supporting the person suffering from dementia to maintain some of their abilities
- Providing caregivers with relaxation and helping them feel less stressed

14.3. Contribution of Internet to Social Life

The internet environment, which is a part of the daily life of people of all ages, in other words, the virtual world contains many elements of interpersonal communication.

It can increase interpersonal communication such as getting to know new people, chatting, sharing ideas, being a member of various groups.

In today's world, people can meet their needs by connecting to the Internet at any time and place during the day, freed from spatial addiction in most cases, such as chatting with friends or relatives, sharing their ideas or being a member of various groups.

For the elders who have spatial addictions and have difficulty leaving the house due to the health problems brought about by old age, the use of the Internet can offer some opportunities in terms of expressing themselves and communicating with the social environment.

The use of the Internet can provide the elders with advantages such as staying in daily life, maintaining communication with the social environment, meeting with friends or relatives who cannot communicate face-to-face, accessing news sources, and obtaining information [1,3]:

- Life satisfaction may increase with Internet use in the elders.

- Their loneliness may decrease
- It can increase their self-confidence.
- Technology can help bridging the gap between patients and the people around them to improve the quality of life of people with cognitive disabilities.
- Technology tools such as iPods can help people with dementia solving cognitive problems.

The use of aiding technologies has significant potential benefits as well as unique challenges. Aiding technology can never replace human contact and interaction. Use in this direction may cause feelings of isolation and loneliness in the individual suffering from dementia. For this reason, attention should be paid to the use of Internet and technology for a long time.

14.4. What Should Be in Mobile Applications?

Some aiding technologies (for example, tele-care or remote monitoring) are focused on increasing safety and reducing risk. The products may not have been designed with the specific needs of individuals suffering from dementia in mind, as a result of which there may be less focus on this issue. Therefore, it is anticipated that the individual will comply with the technology rather than the technology being compatible with the individual suffering from dementia. Waiting for the person suffering from dementia to adapt himself/herself without listening to their opinions may affect their willingness to use technology. It will have an impact on how successful the application is. Aiding technologies, especially more advanced devices, can also be extremely expensive, especially for elders who pay for their own care. Therefore, there is a need to develop free applications [*3*].

The use of technology has an important role in improving the quality of life of the elders. There is a need to develop Internet and computer applications for Alzheimer’s patients and the elders.

In mobile applications, it should be aimed to increase the skills of cognitive thinking, communication, making logical decisions, behaving clearly, and using memory actively [1,4-8]:

- There should be **games** to increase the cognitive skills of dementia patients
- **Mood regulating practices** should be included in dementia patients.
- **Applications** for the care of dementia patients should be included.
- **Practices** for the physical health of dementia patients should be included.

- Practices should be included to improve the **mental state** of caregivers resulting from the burden of care.
- **Educational information on how to use computers and mobile phones** for dementia patients and their caregivers should be included.
- There should be an area where **pictures** can be uploaded to help dementia patients remember daily events.

Wandering is one of the most common behaviors exhibited by people with dementia. Wandering increases the burden on family caregivers to keep the dementia patient safe, which may compel them to consider institutional care. Mobile technology can help solving this problem by providing detailed location information using GPS or photography and providing alerts when motion is detected outside a preset digital fence. Both approaches provide peace of mind and should include a system to help caregivers find a missing family member as quickly as possible. For location tracking, systems often require dementia patients to carry a GPS-integrated mobile device in a pocket, shoulder or waist bag, or waist belt for continuous monitoring. An application should be developed that uses a registered mobile phone to send geographic information to a server at predetermined time intervals to monitor and alert caregivers based on predefined parameters. GPS-integrated mobile phones can also be used to define a security zone. Where a person moves out of this area, an SMS message with location information and a map can be sent to the caregiver's phone [*5*].

Studies show that using smartphones or iPods helps improving cognitive abilities in Alzheimer's patients. There is a vital need to develop assistive technologies, especially for dementia, which is relatively associated with dementia. It explains that a mobile application that can help Alzheimer's patients better can have vital features. It also helps relieving the mental and economic burden on caregivers as well as on patients [*7*].

Alzheimer's patients are sensitive to music. Therefore, the brain of the patient should be an area where he can be stimulated by playing his favorite tones and loaded with music [*4*].

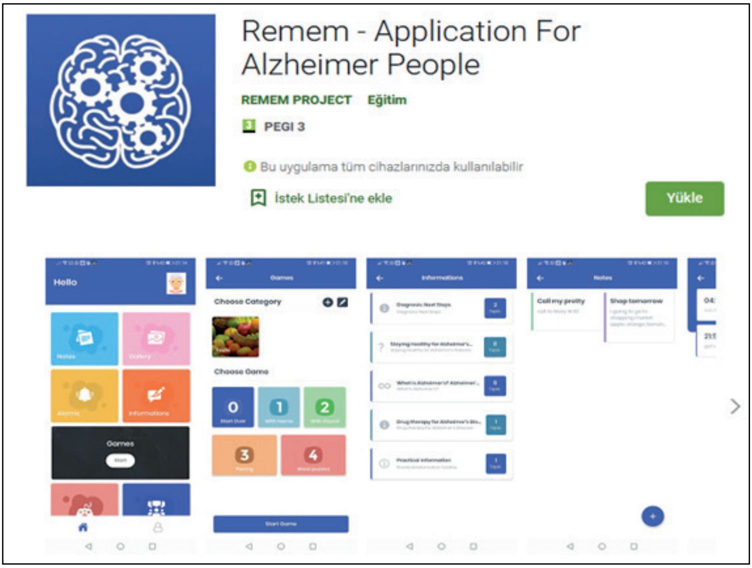
14.5. Which Mobile Applications Can Be Used?

In the early or mildest stage of dementia, there are many things that can be done to help the person maintain as much independence as possible and to help keep their brain active and possibly slow the onset of mid-stage.

Most people today have a smartphone or tablet device with all kinds of applications installed. There are also many applications on the market that can be beneficial to Alzheimer's patients. We have compiled the applications that we think will be useful among them.

14.5.1 REMEM

REMEM is an easy-to-use mobile application designed to meet the daily needs of Alzheimer's patients and their caregivers. This practice is based on the experience of patients as well as caregivers and their relatives [*10*].



Remem - Application For Alzheimer People

REMEM PROJECT Eğitim

PEGI 3

Bu uygulama tüm cihazlarınızda kullanılabilir

İstek Listesi'ne ekle

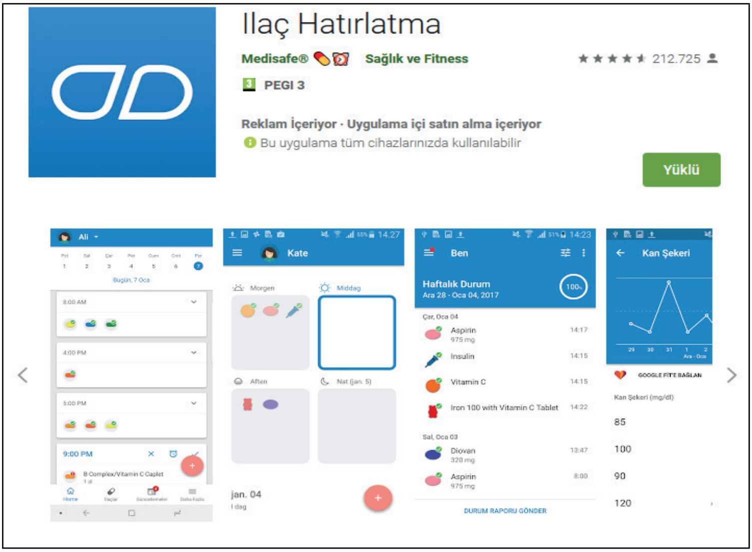
Yükle

Users upload photos of people they want and save them with their names. Then they can start playing games with these photos and names. They do photo, word, and sound matching. These games make it easier to remember the appearance and names of these people in daily life as the questions asked in these games are the information of people they know.

It is available for free on iOS and Android devices.

14.5.2. Medication Reminder (MediSafe - Meds & Safe Pill Reminder) application

People with dementia typically have short-term memory problems and may forget to take their regular medication. This application is the one that allows to alert them when it is time to take various types of medicines and when it is time to reorder a prescription. It was developed for Android mobile phones (*11*).



Ilaç Hatırlatma

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PEGI 3

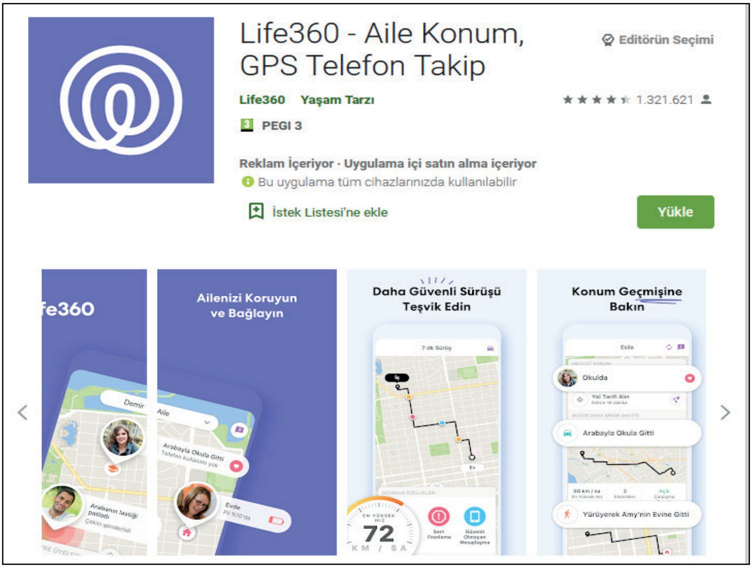
Reklam İçeriyor · Uygulama içi satın alma içeriyor

Bu uygulama tüm cihazlarınızda kullanılabilir

Yüklü

14.5.3. Life 360 – Family Locator GPS Tracker

People with dementia often forget where they are or where they should be. This application allows family members to track each other, provided the device is with them and GPS is enabled (*12*).



Life360 - Aile Konum, GPS Telefon Takip

Editörün Seçimi

Life360 **Yaşam Tarzı** ★★★★★ 1.321.621

PEGI 3

Reklam İçeriyor · Uygulama içi satın alma içeriyor

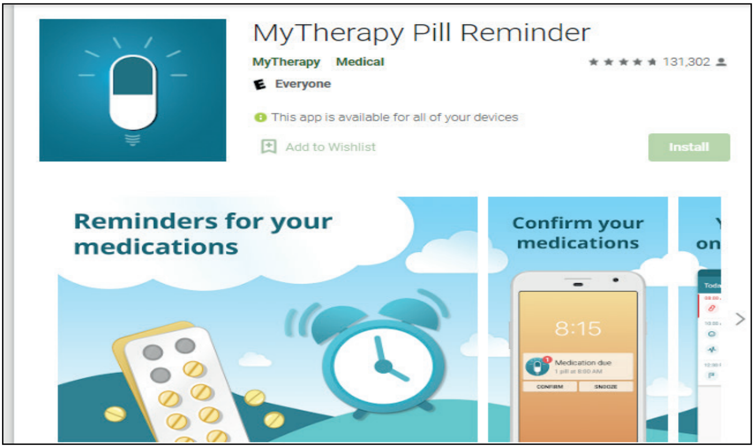
Bu uygulama tüm cihazlarınızda kullanılabilir

İstek Listesi'ne ekle

Yükle

14.5.4. MyTherapy Pill Alarm & Reminder, Health Assistant

MyTherapy provides peace of mind to people with dementia and their families. It has comprehensive blood pressure, blood sugar, etc. monitoring features in easy-to-use charts as well as medication reminders. Many physicians also use the MyTherapy application's built-in reports to better understand their patients' progress. The effectiveness of the application has been scientifically proven by Europe's largest university hospital, Charité Berlin. It is available for free on Android and iOS (*13*).

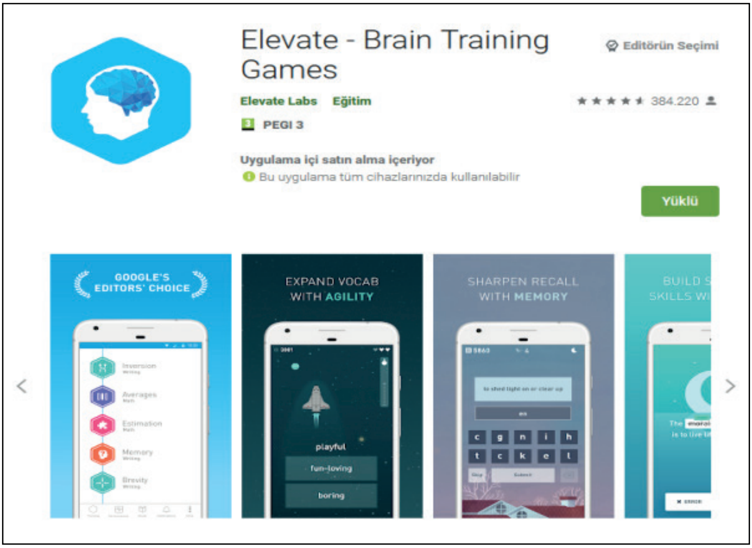


MyTherapy Pill Reminder

This app is available for all of your devices

14.5.5. Elevate Brain Training Games

It was designed to improve cognitive skills and increase confidence. With this application, you can improve your cognitive functions. However, this is especially important for someone with dementia. This application allows people to do more than 35 different activities and puzzles to improve their brain function. It is available for free on Android and iOS (*14*).



Elevate - Brain Training Games

Editörün Seçimi

Elevate Labs Eğitim

★★★★★ 384.220

PEGI 3

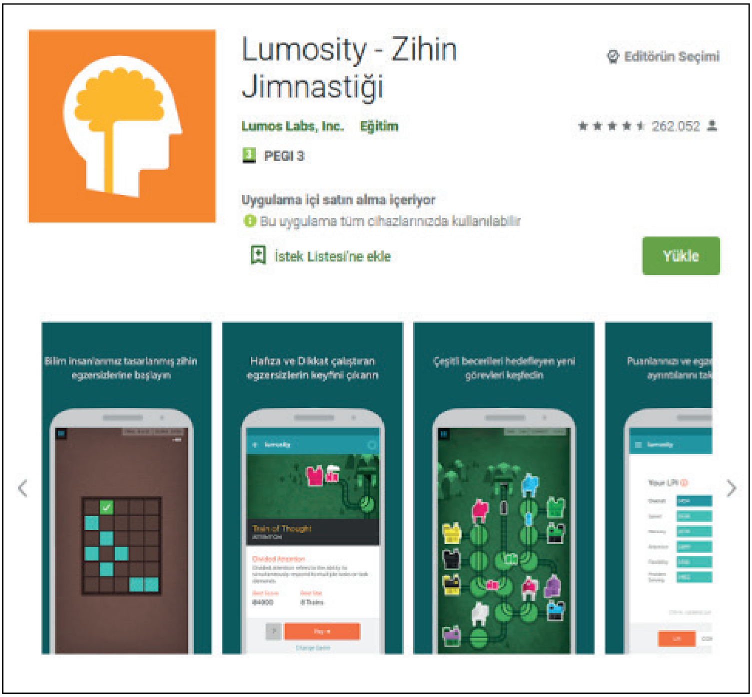
Uygulama içi satın alma içeriyor

Bu uygulama tüm cihazlarınızda kullanılabilir

Yüklü

14.5.6. Lumosity Brain Training

It is an application designed to improve memory, interest, and other cognitive abilities through daily activities and games. This application designed by a team of scientists offers a variety of cognitive and neuropsychological tasks that boost brain function. Available for free on Android and IOS (*15*).



Lumosity - Zihin Jimnastiği

Lumos Labs, Inc. Eğitim

PEGI 3

Uygulama içi satın alma içeriyor

Bu uygulama tüm cihazlarınızda kullanılabilir

Bilim insanlarımız tasarlanmış zihin egzersizlerine başlayın

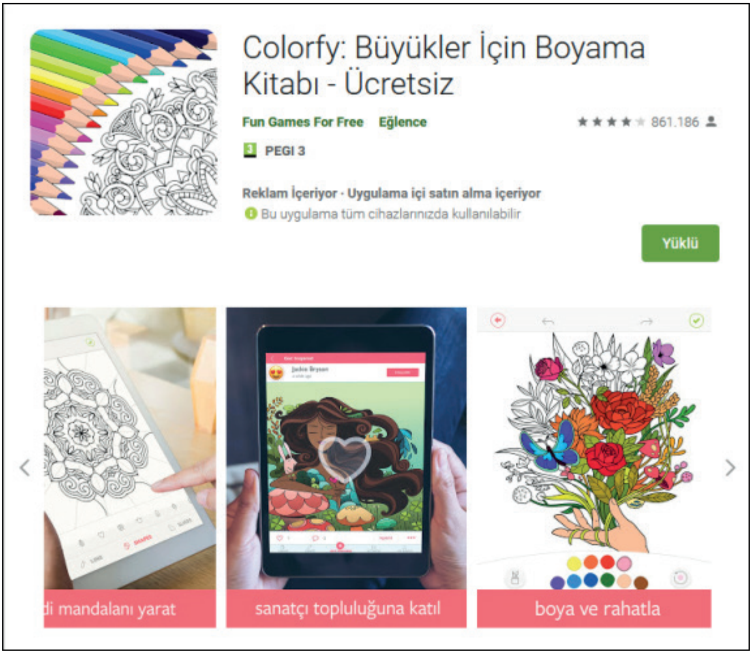
Hafıza ve Dikkat çalıştıran egzersizlerin keyfini çıkarın

Çeşitli becerileri hedefleyen yeni görevleri keşfedin

Puanlarınızı ve egze ayrıntılarını tak

14.5.7. Colorfy Colouring for Adults

Colouring daily life is an application that provides relaxation. It increases the awareness of the individual and helps focusing the mind on something. This application is full of images like flowers, animals, cats, nature, and famous pictures. Available for free on Android and iOS devices (*16*).



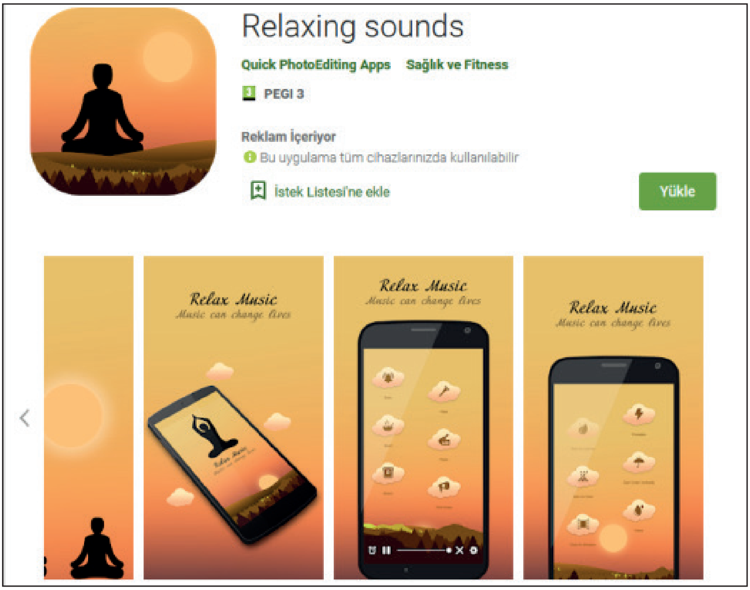
Colorfy: Büyükler İçin Boyama Kitabı - Ücretsiz

Reklam İçeriyor · Uygulama içi satın alma içeriyor

Bu uygulama tüm cihazlarınızda kullanılabilir

14.5.8. Relaxing Sounds

Living with dementia can make people feel stressed, depressed, and anxious, so it’s important to relax. This application contains a wide variety of soothing nature recordings designed to create a calm relaxing and calming environment for the listener. Sounds include forest and camp-fire, sea, river and waterfall, bird and other animal sounds (*17*).



Relaxing sounds

Quick PhotoEditing Apps Sağlık ve Fitness

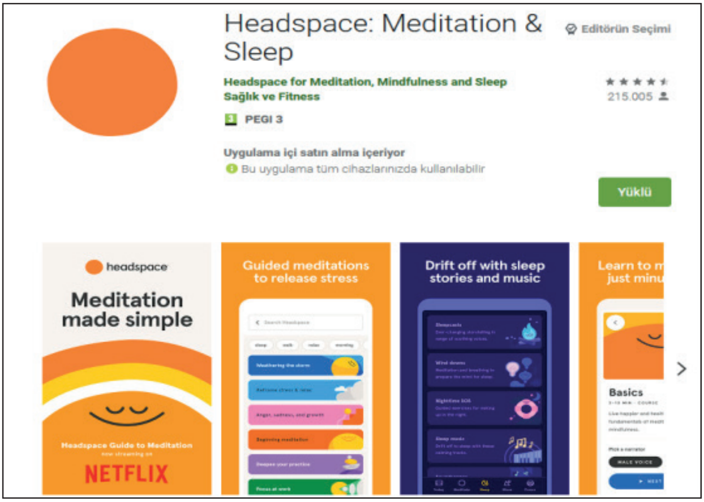
PEGI 3

Reklam İçeriyor

Bu uygulama tüm cihazlarınızda kullanılabilir

14.5.9. Headspace Meditation

Memory loss, confusion, and mind fog can be stressful and distressing for someone with dementia. Meditation and mindfulness can be helpful when things are too busy for users and this application guides the user through a series of short meditations. It is free to download initially. However, users will have to pay to unlock additional materials (*18*).



Headspace: Meditation & Sleep

Headspace for Meditation, Mindfulness and Sleep
Sağlık ve Fitness

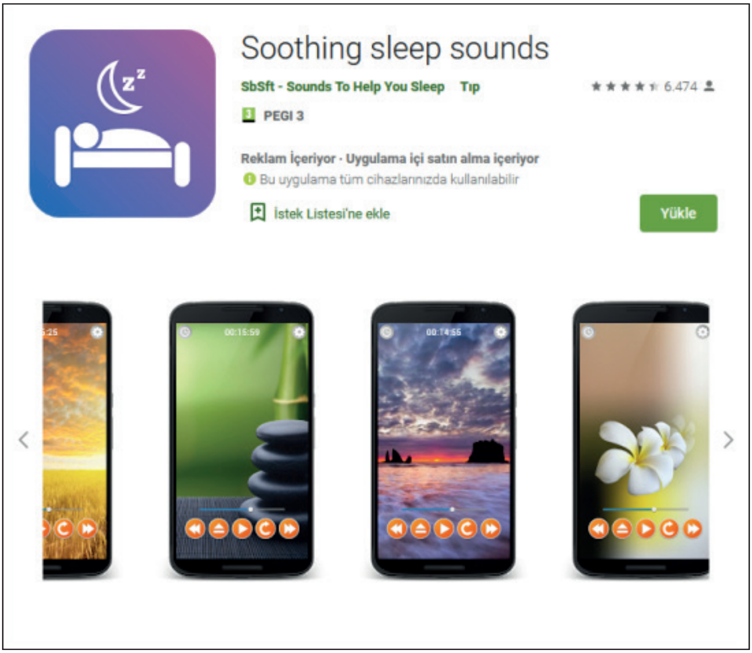
PEGI 3

Uygulama içi satın alma içeriyor

Bu uygulama tüm cihazlarınızda kullanılabilir

14.5.10. Shoothing Sleep Sound

People with dementia can sometimes lose track of the time of day or night, which can later affect their sleep cycles and lead to insomnia. This application with soothing sleep sounds is designed to offer sounds that will put you to sleep. It includes an extensive catalogue of relaxing music. Available for free on Android and iOS devices (*19*).



Soothing sleep sounds

SbSft - Sounds To Help You Sleep Tıp

★★★★★ 6.474

PEGI 3

Reklam İçeriyor · Uygulama içi satın alma içeriyor

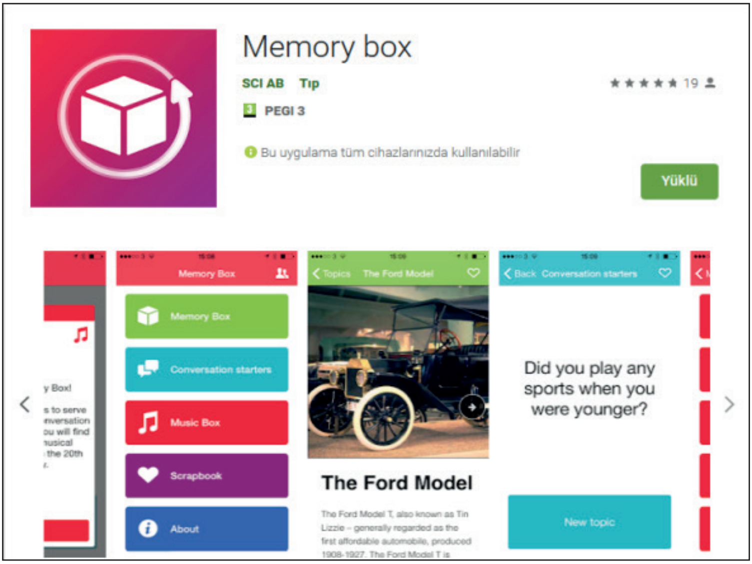
Bu uygulama tüm cihazlarınızda kullanılabilir

İstek Listesi'ne ekle

Yükle

14.5.11. Memory Box

This application is intended to serve as a memory aid and to provide conversational inspiration for relatives and caregivers of patients with dementia. It contains information regarding famous people, places, topics, and events from the 20th century that can help conversations. There is also an album to save your favourite memories. It is available for free on Android devices (*20*).



Memory box

SCI AB Tıp

PEGI 3

Bu uygulama tüm cihazlarınızda kullanılabilir

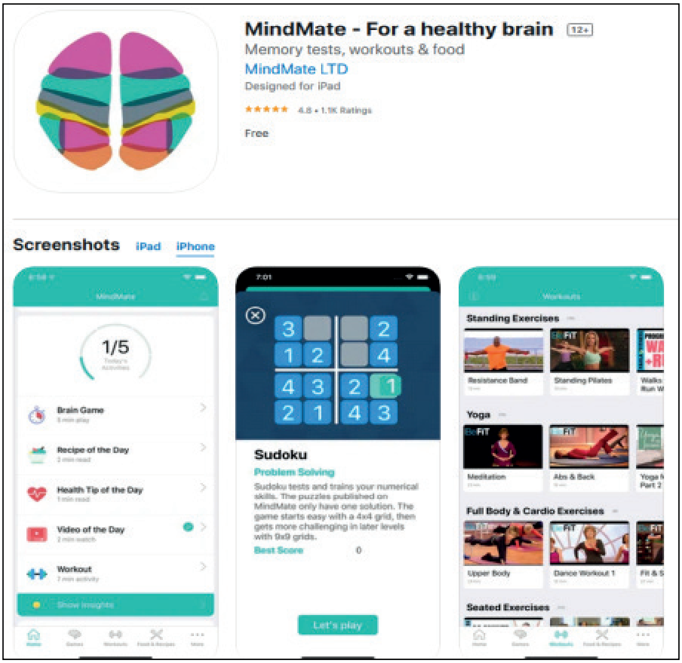
Did you play any sports when you were younger?

The Ford Model

The Ford Model T, also known as Tin Lizzie – generally regarded as the first affordable automobile, produced 1908-1927. The Ford Model T is

14.5.12. MindMate

Created by AppInstitute, this application is for relatives, caregivers, and emergency room personnel working with people with dementia in emergencies. It includes recommendations on how to approach and communicate with someone with moderate to late-stage dementia who may be anxious or upset, as well as guidance on dealing with specific situations. Free and paid versions are available for iOS devices (*21*).



MindMate - For a healthy brain 12+

Memory tests, workouts & food

MindMate LTD

Designed for iPad

★★★★★ 4.8 • 1.1K Ratings

Free

Screenshots iPad iPhone

Sudoku

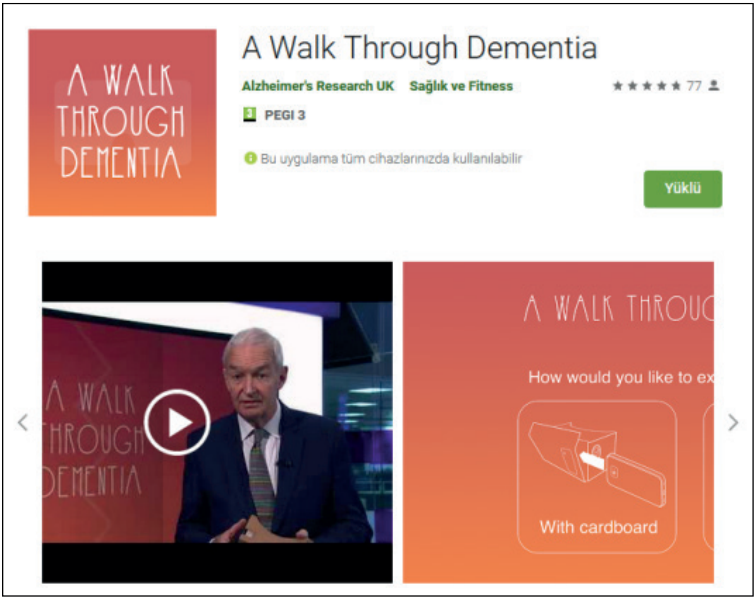
Problem Solving

Sudoku tests and trains your numerical skills. The puzzles published on MindMate only have one solution. The game starts easy with a 4x4 grid, then gets more challenging in later levels with 9x9 grids.

Best Score 0

14.5.13. A Walk Though Dementia

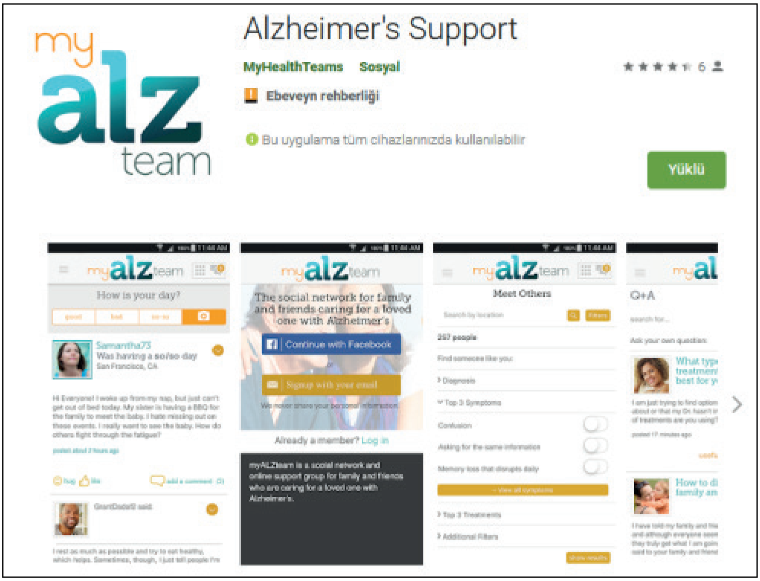
This innovative virtual reality application allows users to understand what life is like for a person with dementia. It uses a combination of 360-degree video sequences and computer-generated environments to show how even the simplest tasks can be difficult for a person with dementia. It is available for free on Android devices (*22*).



Bu uygulama tüm cihazlarınızda kullanılabilir

14.5.14. My ALZ Team

MyALZteam is a social network and support group for family and friends caring for someone with Alzheimer’s. It is created for people who need emotional support and for users who want to get practical tips related to managing living with Alzheimer’s and getting preliminary information related to treatments or therapies. MyALZteam is a social network where you can truly connect, make real friendships and share daily ups and downs in a place without judgment. It is available for free on Android (*23*).



Bu uygulama tüm cihazlarınızda kullanılabilir

The social network for family and friends caring for a loved one with Alzheimer's

myALZteam is a social network and online support group for family and friends who are caring for a loved one with Alzheimer's.

14.5.15. YoTeCuido Alzheimer

YoTeCuido is a very easy to use application designed to answer the doubts and questions many caregivers and those affected by Alzheimer's face in their daily lives. Produced by Lapisoft in collaboration with the Association of Relatives of Alzheimer's Patients in A Coruña (AFACO), this company's content is based on the experiences of patients and professional caregivers, as well as caregivers and family members. The application language is Spanish and is available for free on Android (*24*).

YoTeCuido Alzheimer

LapiSoft Sağlık ve Fitness

★★★★★ 154

PEGI 3

Bu uygulama tüm cihazlarınızda kullanılabilir

til herramienta
el día a día de
lores y enfermos

Toda la información
que necesitas en
una práctica app

Encuentra respuesta
a tus dudas sobre
comida, salud...

Accede a contenido
útiles y explicados d
forma sencilla

Websites with links below can also help patients and their relatives: https://www.alzheimersresearchuk.org/ https://www.helpforalzheimersfamilies.com/ https://www.alz.org/ https://www.alzheimerdernegi.org.tr/

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4. 2018 Fifth International Conference on Parallel, Distributed and Grid Computing (PDGC)
5. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6878101/
6. https://www.uksmobility.co.uk/blog/2016/07/25-useful-apps-for-dementia-patients-and-carers/
7. Biological Forum–An International Journal ISSN No. (Online):2249-3239. Mobile Health Applications and Android Toolkit for AlzheimerPatients, Caregivers and Doctors
8. Studies Involving People With Dementia and Touchscreen Technology: A Literature Review https://rehab.jmir.org/2016/2/e10/ıutm_campaign=JMIR_TrendMD_0&utm_medium=cpc&utm_source=TrendMD
9. https://dergipark.org.tr/en/download/article-file/907864.
10. https://remem.eu/
11. https://www.medisafeapp.com/
12. https://life360.tr.uptodown.com/android/download
13. https://play.google.com/store/apps/details?id=eu.smartpatient.mytherapy&hl=en_US&gl=US
14. https://apps.apple.com/us/app/elevate-brain-training/id875063456#:~:text=Elevate's%20games%20are%20designed%20in,training%20program%20for%20each%20user.
15. https://www.lumosity.com/en/
16. https://play.google.com/store/apps/details?id=com.fungamesforfree.colorfy&hl=en_US&gl=US
17. https://apps.apple.com/us/app/relax-sounds-relaxing-nature-ambient-melodies-help/id782361353
18. https://play.google.com/store/apps/details?id=com.getsomeheadspace.android&hl=tr&gl=US
19. https://apps.apple.com/us/app/soothing-sleep-sounds/id880195209
20. https://apps.apple.com/us/app/memorybox-app/id1033303683
21. https://www.mindmate-app.com/
22. https://www.alzheimersresearchuk.org/campaigns/awtd/#:~:text=A%20Walk%20Through%20Dementia%20is,dementia%20has%20on%20people's%20lives.
23. https://www.myalzteam.com/

CHAPTER 15

ALZHEIMER’S PATIENT RIGHTS AND LEGAL ISSUES

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Chapter Content

15.1. Introduction

Dementia disrupts all the knowledge and skills that a person acquires in the process of turning into an adult, making them inadequate. In this way, patients gradually become in need of protection. They are no longer ordinary individuals. They need special protection and regulations for the protection of their rights. Legal regulations have brought special protection provisions for individuals who are incompetent compared to others for various reasons. What is tried to be ensured by these regulations is the attainment of a disability-free standard of living for people with disabilities. Children, those with mental illness, those with mental weakness and the like are in this group. In legal regulations, there are sometimes general expressions covering all of them, and sometimes the opportunities brought by the law through "comparison" protect people with disabilities by including them within the scope of the same line. Below, the existing legal regulations on the subject have been tried to be examined. It is necessary in these regulations to evaluate the expressions describing the target audience in the light of these explanations.

This section focuses on bioethical and legal aspects. Bioethical aspects concern the bioethical aspects of particular importance: personal identity and awareness, communication of the diagnosis (at a pre-symptomatic level and symptomatic), the therapeutic relationship (with reference to informed consent, pain treatment), comprehensive symptomatic treatment, the theme of food (natural and artificial), social and health care and new technologies, information, and social training.

In the legal sphere, the problem is framed in the general context of law and mental health. In particular, the legal instruments for protecting forms of dementia (support administration, interdiction, incapacitation) are analyzed, also with reference to the legislation on compulsory health treatment. The possibility of advance treatment declarations is also analyzed, as a tool that strengthens informed consent in medical choices, in anticipation of the progressive loss of full possession of patient's faculties.

15.2. The Problem of Personal Identity and Awareness

The progressive impoverishment at the structural level and the consequent functional impairment at the cerebral level (together with marked behavioral changes that can also lead to aggressive manifestations) determine substantial changes in the patient's personality so as to lead family members and acquaintances to no longer recognize the subject, with the consequent suffering of the difficulty of carrying on the emotional bond, which can take the form, in some cases, of particular gravity as a real sense of loss. In parallel, the patient diagnosed with dementia, especially if he/she suffers from Alzheimer, undergoes a progressive but inexorable impairment of memory functions. Impairment of memory functions may also determine manifestations of spatial and temporal disorientation (the subject may not recognize the environment in which he is, despite being a very familiar place) and misidentification (e.g., mistaking family members for other people or even strangers). This generates in the patient, from the initial phase of the disease, serious psychological suffering, from anxiety for the future connected to the fear of dependence and the loss of autonomy and decision-making capacity to existential disorientation, due to the progressive difficulty of "*recognizing*".

It is believed that the dementia sufferer should be recognized as a person at every stage of the disease, regardless of the gradual or immediate change in cognitive conditions or by the change of personality and behavior: this recognition justifies the dutifulness of treatment and assistance, by doctors, family and society. The unconsciousness condition or gradual loss of consciousness and the related difficulty should not be used as a justification for an ethical consideration of inferiority and a decrease in the recognition of dignity. This would introduce dangerous forms of discrimination that violate the principle of equality - the cornerstone of human rights - which recognizes equal dignity to every human being on the basis of being and not of doing or possessing certain capacities.

The question remains as to whether this involves a change in the sense of subjective identity of the patient, i.e. the subjective state of awareness of psychological sensations (cognitive, affective and emotional) and perceptual reports to both the internal and external worlds. In this context, various components of self-awareness can be distinguished such as the ability:

- to perceive external and internal stimuli agents on the individual (self-detection);
- to remember the actions carried out and to predict the outcomes of the self-monitoring and self-agency behaviors;
- to perceive the body as its own, to recognize its image in the mirror, to recognize themselves as the subject of one's own experiences (self-recognition and self-ownership);
- to build a consistent representation of self-knowledge.

These meta-cognitive functions in dementias usually cause profound alterations. Unlike other conditions such as brain trauma or stroke, in dementia the loss of awareness is irreversible and progressively increscent.

15.3 Diagnosis and Communication of the Diagnosis

As already mentioned, today there is a growing international trend to develop early detection algorithms using innovative techniques.

The obvious and immediate advantage of this approach is to access targeted prevention interventions that could improve the quality of life of the patient and the course of the disease, as well as the possibility of planning therapeutic and assistance treatments. However, this also carries risks and leave some central questions open: is useful to formulate a diagnosis at the first appearance of symptoms? Is there no risk of “delivering” a reality to the patient that can be experienced as an inevitable condemnation? It would remain also to establish to whom the diagnosis should be communicated in stages like this precocious (only to the patient or also to family members, within the limits of the right to privacy required by our legal system?). Not to mention that some of the tools that allow advance diagnostic hypotheses in pre-symptomatic symptoms stages of the disease do not always return certain answers (thus leaving ample room for the clinician’s interpretation) and do not take into account subjective factors of resilience. It is also debated whether it is morally relevant increasing the research in the direction of diagnostic anticipation and to the extent that research offers concrete opportunities in this sense.

Furthermore, it is also debated what extent to open the pre-symptomatic diagnostic access even through mandatory screenings or only to those who are more susceptible to the disease on the basis of medical indications shared by the scientific community. This ethical discussion is intertwined above all with the economic-health consideration: one wonders how much the health system is willing to support - in terms of costs - for instrumental examinations and biological / neurological predicted for an incurable disease, and how to balance those expenses with respect to therapeutic-assistance costs.

A communication of the diagnosis, that takes place in a dialogical context, can endure, and manage to combine, according to a basic principle of ethics and medical ethics. ‘The right to truth’ with the ‘right to hope’ can lead numerous benefits: the patient’s understanding of his own experience, the opportunity to access appropriate services, the planning of one’s own life. Although the value of confidentiality must be recognized, given the necessary involvement of family members in caring for the sick, is important that they are aware of the diagnosis. The doctor must encourage the sick himself to report his illness to his family, albeit in the understandable reticence. There may be exceptions to the general rule when there is a conscious refusal on the part of the patient to inform family members.

The mode of communication is difficult and requires special skills, psychological and empathic capacity, and deep human sensitivity. There are many authors who provide information on the methods and aspects to consider in communicating the diagnosis. There is unanimous consent to provide psychological support to reassure patients and family members on the available resources and treatments, and to give information [*1*] about the necessity to carry out an assessment of the individual's personality for prevent negative reactions by assuming an empathic attitude during the conversation. However, these indications, correct and clearly dictated by the good sense, are not always reflected in clinical practice and perhaps more than that on the concept of diagnosis, attention should be focused on the concept of factor risk, duly relativized.

The basic principle of any clinical measure, including the communication of a diagnosis, should unavoidably act in the interest of the patient.

15.4. The Cure

The Patient-Doctor Therapeutic Relationship

The physician must inform the patient correctly and objectively on the course of the disease and on the real possibilities of treatment. The target of the doctor must be, in a consistent manner with deontology and medical ethics, a continuous dialogue with the patient that is not limited to describe in neutral way the stages of the pathology and the options for possible treatments (and their limitations), but also try to accompany the patient in the acceptance of the disease and of the therapeutic-assistance path.

Informed Consent

As long as the patient is able to make decisions and there is demonstration of the contrary, the patient's autonomy, his choices and his own guidelines have priority. The diagnosis of AD, as mentioned, does not necessarily imply the loss of decision-making competence. In the early stages, the patient can have lost some of the cognitive functions and therefore he is not able to manage autonomously some aspects of his life but still own one sufficient decision-making capacity in some fields (for example, decisions treatments or participation in experiments and research). The ability of decision making of the demented patient varies enormously according to the state of progression of the disease. Decision-making autonomy in the demented patient needs therefore to be considered as a dynamic concept and needs to be evaluated in the different phases of illness, in relation to the type of decision to be taken. Unfortunately, standardized tools that define the competence of an individual suffering from dementia still do not exist. Therefore, neuropsychiatric research's task is to define protocols that evaluate the different dimensions and the functional aspects, underlying the decision-making process, in order to involve - as far as possible - the patient in therapeutic decisions and welfare.

15.4 Law and Mental Health

The protection of the patient with dementia in the context of the protection of mental health.

Like any human being, the Alzheimer's patient - at every stage of the disease and at any age considered - has the right to the protection of his or her dignity, of his rights and to the protection and health care, according to the Constitution and the laws of the State. These needs are translated into strengthening the rights of patients and their families, in combating prejudice and discrimination and in adopting appropriate policies and legislative instruments. This strategy of respect for human rights is a program that unites international and European texts on mental health, those of the *WHO, the UN, the European Union, the Council of Europe*. There are many charters that recommend national legislations to guarantee the rights of people with mental disorders, including their right to appropriate medical treatment. Several rules have been defined with the invitation to become the object of elaboration in national legislation. These focus on various aspects.

Although the recommendations - translated into rules aimed at affirming the rights of people with dementia - have obliged several states to review their legislation in order to comply with these, it should be noted that the introduction of these rules into national legislation cannot be sufficient, if not accompanied by a new will to take charge of mental health. To develop such a policy, it is essential that the views of patients and their families are taken into consideration, as much as that of professionals. It is also essential to give support and help to the families of the patient since, as experience shows, voluntary or involuntary treatments are effective only if there is strong community support in the subject's living environment.

Legal instruments for the protection of the dementia patient (Italy)

Most of these recommendations have been widely considered by our legislator. The legal tools to protect forms of dementia, which can progressively affect full possession of the patient's faculties, are given by the "support administration" (art. 404 et seq. of the civil code), by the "disqualification" and "incapacitation" (art. 414 et seq. of the civil code).

The legislation does not clearly indicate selective criteria to distinguish the use of one or the other measures and therefore these give rise to three "partially fungible" legal cases and leave the choice of the concretely applicable instrument to the decision of the judge.

From a jurisprudential point of view, there is no doubt that the most widely used instrument is that of the support administration (*Law n. 6/2004*). This is very similar to the German guardianship law (*known as the Betreuungsgesetz*) and means that the guardianship court appoints a person who is deemed capable of suitably looking after the patient and his/ her interests. At present, "the only law applicable to guardianship is this new one, even though it doesn't repeal the previous rules of judicial disability (loss of fundamental basic rights which are acquired with adulthood) and judicial disqualification (incompetence to carry out business). This law involved a notable change of the whole section of the Italian civil code traditionally dealing with "infermità di mente" (insanity), "interdizione" (judicial disability) and "inabilitazione" (judicial disqualification). At this stage, the title of this section is "provisions for the protection of people who are partly or wholly unable to look after their own affairs [*2,3*].

This new law applies to people who are unable to look after their affairs due to major illness or permanent disability. The goal of the new rules is to balance the opposing needs for independence and protection, granting people as much freedom as possible and, at the same time, ensuring that they are provided with necessary protection that is proportionate to their needs and fair. In the case of "support administration", the guardianship court appoints a guardian following a hearing. The duties of the guardian appointed are:

- ➢ to get acquainted with, evaluate, and notify the Guardianship Court about the circumstances and needs in the life of the beneficiary.
- ➢ to represent and look after the beneficiary with the sole purpose of handling his/her affairs in accordance with the powers which were conferred on him expressly by the Guardianship Court.

After the guardian has been appointed, the beneficiary of "support administration" remains legally competent and has the power to manage all acts for which the Guardianship Court did not grant power to the guardian. In any case, s/he can manage by himself/herself whatever is necessary for his/her everyday needs (e.g., the purchase of clothes and food).

Only if there are no interventions in this area suitable to ensure sufficient protection to the incapable patient, the judge will resort to the most invasive measures of incapacity or interdiction, which attribute a status of incapacity, extended for the incapacitated to acts of extraordinary administration and for the disqualification also to those of ordinary administration.

The request for interdiction and for appointing a guardian is made with an appeal, containing the presentation of the facts on which the request is based, directed to the Court of the place where the person to be interdicted has his effective residence or domicile. In the case of a permanently hospitalized person, the application must be presented to the Court of the place where he lives. The President of the Court communicates the appeal to the Public Prosecutor, who, after evaluating the application, may request its rejection by a decree. If this does not happen, the President appoints the investigating judge and sets the hearing for the appearance of the person who presented the request, the interdicting party and all those which are named in the application. With the sentence declaring the interdiction, a guardian is appointed, and the management of the interdict's assets and the related acts are entrusted to the guardian of the incapable person.

There is no doubt that in the case of support administration the legislator intended to configure an elastic instrument, modeled according to the needs of the specific case, which differs from the interdiction not so much from a quantitative as from a functional point of view. This leads us not to exclude that in general in the presence of particularly serious pathologies, both one and the other protection instruments may be used and that, as already mentioned, only the specificity of the individual cases and needs, to be met from time to time, can determine the choice between the different institutions. In fact, the prohibition has a residual character, intending the legislator to reserve it in consideration of the seriousness of the effects that derive from it to the hypothesis in which no protective efficacy would result in a different measure (Corte Cost., N. 440/2005; Cass . civ., n. 12466/2007 and Cass. civ., n. 9628/2009). Especially in the case in which interdiction is requested, the mental illness must be current and habitual, therefore stable, and sufficiently protracted over time. The concept of habituality should not be confused with continuity: the existence of clear intervals, lasting, does not represent an obstacle to the declaration of interdiction or to the administration of support.

The family - in all the cases described - is not “excluded” from the decisions of the judge; but certainly, compared to what happened in many cases in the past, there is a greater tendency to examine as far as possible the residual faculties of the dementia patient in decision-making terms, through “dialogue” and a greater understanding of his interests.

Moreover, the Italian State offers through the National Institute for Social Security (INPS) economic assurance for both partial disability and total disability [*4*].

For partial disability, the monthly allowance is an economic benefit of a welfare nature granted to partial invalids between the ages of 18 and 67 (this term is subject to the periodic review, by the government, of the retirement age in relation to life expectancy), with a reduction in working capacity of between 74% and 99%, which meet the health requirements and required by law. Once the health and administrative requirements have been ascertained, the benefit is paid for 13 months starting from the first day of the month following the submission of the application.

On the other side, regarding the people with total disability, the INPS recognizes an accompanying allowance for people whom it has been ascertained that it is impossible to walk without the help of a companion or the inability to carry out daily activities. For the 2021, the amount for the allowance is of 522,10 Euro per month.

15.5. Power of Attorney

As long as the person with dementia has the legal capacity (*ability to understand and appreciate the consequences of their actions*), they should be involved in legal planning.

When the person with dementia is unable to take responsibility for themselves, a spouse, roommate, trusted family member, or friend (called an attorney or surrogate) is often appointed as an attorney to make financial and other decisions for a person with dementia. Thus, a power of attorney is issued.

It is recommended that this individual have a thorough discussion with authorized persons as to what responsibility means. Power of attorney documents must be written to be “durable”, meaning that once the person is incapacitated, they can no longer make their own decisions.

When the client cannot make a decision, he/she is authorized to manage the client’s income and assets. The representative is responsible for acting according to the client’s wishes and in the best interest of the person.

As Alzheimer’s patients cannot use their mental abilities correctly and adequately, it is important to take custody of a healthy relative who takes care of them in order not to cause any legal negativity against them and their relatives. This is because Alzheimer's is a mental and spiritual illness, it lacks the ability to appeal.

15.6. Rights for Alzheimer's Patients and Their Relatives

Alzheimer's patients and their relatives may not be able to use all the rights granted to disabled people due to the patient's age and mental and spiritual disability. Only the rights enjoyed by Alzheimer's patients will be mentioned here. We can list these rights as follows:

- Disability pension,
- Home care pension for relatives,
- Utilization from a nursing home
- Pension
- Disability retirement,
- Obtaining device,
- Medical supplies,
- There are legal regulations on property tax and tax deductions.
- Also, discounted, or free transportation services are offered by municipalities for the elderly and disabled.

An attorney can be consulted on how to obtain these rights, or information can be obtained from Alzheimer's associations in the countries and on the relevant websites of the associations [5,6].

15.7. Law Articles on Alzheimer's Patient Rights and Legal Issues

Below are articles on legal rights for Alzheimer's patients and other disabilities.

15.7.1. Convention on the Rights of Persons with Disabilities

This International Convention dated 13.05.2009 aims to improve the rights of the disabled at the wider level of the masses and to bring standard practices (*7*). Article 1, Article 19, and Article 26 are added as ***Annex1***.

15.7.2. Constitution of the Republic of Turkiye

The basic operating rules of the communities the social and political order are regulated by the Constitutions of the countries. In Turkiye, the fundamental rights and duties of citizens are determined by Turkish Constitution (*4*).

Article 12 - *Everyone has fundamental rights and freedoms that are personal, inviolable, inalienable, and indispensable.*

Article 17 - *Everyone has the right to live, to protect, and develop their material and spiritual existence.*

Everyone is equal before the law. However, achieving this equality may require positive discrimination. It is an inevitable requirement to provide the equality that natural conditions do not offer with legal regulations. We realize it with our Civil Code, Penal Codes, and the like, that is, with our special legal regulations that are compatible with the Constitution.

15.7.3. Turkish Civil Code

What are Alzheimer's patients capable of and what are they limited? What provisions provide for this and how? All these issues, as explained above, are stipulated in the Turkish Civil Code for those with Alzheimer's and similar disabilities. The provisions regarding the subject are selected and listed as ***Annex 2***.

It is controversial whether dementia as a medical term is a mental illness. "*Weakness of mind*" was not mentioned among the reasons for divorce. The grounds for divorce related to mental illness also seem applicable in the case of dementia by analogy.

Having a right is not the same thing as being able to do what is necessary. The "inviolable, inalienable, and indispensable fundamental rights and freedoms" guaranteed by the Constitution can only be exercised by "fully competent" individuals who "have the power to discriminate". Individuals who have partially or completely lost this ability are granted these rights within the framework of special protection rules. Those who do not have the power to discriminate are expressed as fully incompetent. Those who have the power to discriminate partially are defined as limited incompetence.

The ability of a person to act in a rational way and to grasp the causes and consequences of his/her behavior correctly is called the power of discrimination.

In the first stage of dementia, the patient has not yet permanently lost his/her power of discrimination. While its accuracy is debatable, it is not yet considered to be placed under guardianship at this stage. Appointment of legal counsel to patients in the initial state may be considered. The application seems insufficient. This is because the degree of the disease requires very good observation. In case that any risk factor becomes a reality, serious problems may occur due to late intervention. The patient may cause situations that will endanger himself/herself or others and leave him/her in a difficult situation, and situations that are difficult or impossible to solve may arise. Also, the legal counsel does not have the opportunities and powers that the guardian has even if the situation is noticed in time. In order to eliminate these drawbacks, we think that the appointment of a guardian in the first stage of dementia is appropriate.

15.7.4. Turkish Criminal Code

Reasons Eliminating or Reducing Criminal Liability

Mental disorder

Article 32 - (1) *A person who, due to mental illness, cannot perceive the legal meaning and consequences of the act he/she has committed, or whose ability to direct his/her behavior in relation to this act is significantly reduced, is not punished. However, security measures are imposed on these persons.*

Article 32 - (2) *A person whose ability to direct his/her behavior in relation to the act he/she has committed, although not to the degree stated in the first paragraph, has decreased, is sentenced to twenty-five years instead of aggravated life imprisonment, and twenty years instead of life imprisonment. In other cases, the penalty to be imposed may be reduced by no more than one-sixth. The sentence given can also be applied partially or completely as a security measure specific to mental patients, provided that its duration is the same.*

It is possible to define all kinds of disorders in the mental faculties as mental illness. This is the view accepted in the doctrine. Any disturbance that reduces or removes the perception ability of the human brain will affect the criminal liability of the person. This is the purpose of Article 32 of the TCK (Turkish Criminal Code). It is not whether dementia is defined as a mental illness or not, what matters is whether the person's ability to perceive the meaning and consequences of the act he/she committed and to direct his/her behavior accordingly has decreased or disappeared for whatever reason. In this regard, the primary problem is to determine at what stage of the disease the patient was actually committing at the time of the incident, that is, whether he/she will be considered "fully capable", "limitedly incapable" or "completely incapable". It will be determined by the official health board examination, for this purpose, the person will be kept under observation if necessary, and the punishment will be determined according to the result to be determined. At the initial stage of the disease, the person can be considered fully competent, that is, having the power to appeal, and a full penalty can be determined. Conditions will be evaluated in each concrete case. In case that the disease is more advanced, a reduction in punishment may be on the agenda, or if the ability to perceive is completely lost, it will be decided that "there is no room for punishment" since it cannot be punished [8].

15.7.5. Law of Criminal Procedure

The relevant parts are given in ***Annex3***.

Perpetrator's Dementia After Committing a Crime: In this case, it will be decided to conduct an expert examination about the person, and the trial will be stopped according to the future result and the penalty will ***be reduced according to the next report. Here, although it is possible that the person may have committed the imputed crime, a person whose ability to defend cannot be prosecuted cannot be prosecuted, and if he is punished, the execution of the sentence will not be possible, as in healthy individuals. Of course, in order to ensure that personal security measures are not imposed, referral to the guardianship authorities shall be ensured, and a guardian shall be appointed to the person, and security measures shall be imposed according to the conditions.***

Since dementia is a progressive disease that does not heal, it will not be possible to postpone the execution of the sentence if the convict suffers from dementia [8].

ABSOLUTE LIABILITY

Liability for wrongful act is based on the fault of the person. It is based on the condition that the person can be held responsible for his faulty actions. As people who do not have the power to discriminate cannot be blamed, these people are not responsible for their wrongful acts as a rule. However, the exceptions to this rule are "perfect liability" cases. We can show the responsibility of equity in the Turkish Code of Obligations as an example of this situation that we come across in various plans. Article 65 - If fairness requires, the judge decides that the damage caused by the person who does not have the power to distinguish is completely or partially eliminated.

In Article 85 of the Highway Traffic Law, the owner and operator of the vehicle are also held responsible for the damage. As it is a state of absolute liability, it does not matter whether the person has the power of appeal or not.

Legal liability of the operator and the owner of the enterprise to which the vehicle operator is affiliated (1) Article 85 - (Amended first paragraph: 17/10/1996- Article 4199/28) If the operation of a motor vehicle causes death or injury to someone or damage to something and if the motor vehicle is operated under the title or business name of an enterprise or with a ticket issued by that enterprise, the operator of the motor vehicle and the owner of the enterprise to which it is affiliated are jointly and severally liable for the resulting damage.

The same liability situations may also be faced by the immovable owner or the limited business owner. It is possible to multiply these examples. In this case, the fact that the person is flawless in criminal proceedings does not remove the responsibility for compensation.

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CHAPTER 16

FROM WHICH ORGANIZATIONS CAN I GET HELP?

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Chapter Content

16.1. Introduction

The 2019 World Alzheimer's Report (drafted by Alzheimer's Disease International - ADI) [*1*] notes that there are over 50 million people in the world with a form of dementia which will become 152 million in 2050, for which a new case of dementia every 3 seconds. Alzheimer's patients have difficulties in performing their cognitive functions. As also highlighted in the preface of the 5th Report of the Non-Self-Sufficiency Network of 2015, assistance to the non-self-sufficient elderly represents a challenge that Italian society is facing, also due to the delay in intervening, or rather not intervened, in reforming the system of public services aimed at them, as opposed to what has happened in countries such as France, Germany and Spain which have envisaged real reforms to guarantee also sustainability. It follows that the growing diffusion in the population, the limited and in any case not decisive effectiveness of the therapies available, the enormous investment in terms of necessary resources (emotional, organizational, and economic) make dementia one of the diseases with the most serious social impact of the world. By its very nature, in fact, dementia creates needs that are not only health-related, significantly affecting the person's living environment and imposing changes and tiring adaptations to the family of the person with dementia, particularly regarding daily care. To cope with this, the World Health Organization (WHO) in 2017 launched the Global Action Plan on Public Health Response to Dementia 2017-2025, which invites governments to achieve specific goals on the front of greater awareness of dementia, risk reduction, diagnosis and assistance, support for family members and caregivers and research.

Patients need support so that they can lose these functions later and achieve a more qualified life. In the first stage of the disease, they often need more emotional and social support. Also, they experience problems with their cognitive functions due to memory confusion that occurs in the early stages. Most of the time, the closest person to the patient starts the care and supervision of the patients. They need patients to better use their cognitive functions to act more independently. In the advanced stage of the disease, patients need a caregiver to provide emotional, social, and daily self-care skills. In Turkiye, the care of the patient is mostly undertaken by the relatives of the patients. Alzheimer's patients need care at all hours of the day. It causes many people to be affected in this process, including their relatives and families. Studies have shown that relatives of patients experience many emotional and social problems. Also, relatives of patients may not have sufficient information as to how to treat patients and what kind of work they should do to ensure their cognitive functions. Therefore, these difficulties experienced by relatives of patients negatively affect the quality of life of both patients and their relatives. For this reason, relatives of many patients may also experience mental problems. In order to overcome these difficulties, patient relatives and patients need to be educated first. On the other hand, there is a need for the existence of appropriate institutions for the qualified care of patients. In parallel with the increase in the elderly population, dementia patients are also increasing day by day.

According to TURKSTAT (2020) data [*2*], ***in Turkiye***, the population aged 65 and over, which is accepted as the elderly population, was 6 million 495 thousand 239 people in 2015, increasing by 22.5% in the last five years to 7 million 953 thousand 555 people in 2020. While the proportion of the elderly population in the total population was 8.2% in 2015, it increased to 9.5% in 2020. In 2020, 44.2% of the elderly population was male and 55.8% was female population (*3*). While the elderly dependency ratio, which represents the number of elderly people per hundred people of working age, was 12.2% in 2015, this rate increased to 14.1% in 2020. According to population projections, it is estimated that the elderly dependency ratio will be 16.4% in 2025, 19.6% in 2030, 25.3% in 2040, 37.5% in 2060 and 43.6% in 2080 (*3*).

According to population estimates, the world population for 2020 is estimated to be 7 billion 693 million 348 thousand 454 people, and the elderly population is 729 million 887 thousand 660 people. According to these estimates, 9.5% of the world's population consists of the elderly population. The top three countries with the highest proportion of elderly population were Monaco with 33.5%, Japan with 28.5% and Germany with 22.9%. Turkiye ranked 66th out of 167 countries (3).

In Italy, the prevalence of dementia ranges between 5.9 and 7.1% of over-sixty-four-year-olds, and therefore differs according to the studies, both Italian and European [*4*]. Since Italians of this age are more than 13 million at the last census [*5*], we are talking about one million people. Population is aging so, looking at the distribution of people with dementia by age, this number is expected to increase. Of this majority, is Alzheimer's. As also highlighted in the preface of the

5th Report of the Non-Self-Sufficiency Network of 2015 ", assistance to the non-self-sufficient elderly represents a challenge that Italian society is facing, also due to the delay in intervening, or rather not intervened, in reforming the system of public services aimed at them, as opposed to what has happened in countries such as France, Germany and Spain which have envisaged real reforms to guarantee also sustainability. It follows that the growing diffusion in the population, the limited and in any case not decisive effectiveness of the therapies available, the enormous investment in terms of necessary resources (emotional, organizational and economic) make dementia one of the diseases with the most serious social impact of the world. By its very nature, in fact, dementia creates needs that are not only health-related, significantly affecting the person's living environment and imposing changes and tiring adaptations to the family of the person with dementia, particularly with regard to daily care. To cope with this, the World Health Organization (WHO) in 2017 launched the Global Action Plan on Public Health Response to Dementia 2017-2025, which invites governments to achieve specific goals on the front of greater awareness of dementia, risk reduction, diagnosis and assistance, support for family members and caregivers and research.

In Romania, the incident is about 270-300,000 people, with a diagnosis rate of between 10-15%. it is not yet recognized that dementia is a public health problem, as no national strategy has been developed for this condition. Considering only Alzheimer's dementia cases and, with the fact that 3-4 people are involved with another person with dementia, the quality of life of at least 1 million people in our country is deeply disturbed. There are 300,000 patients diagnosed with Alzheimer's disease, well above the European average, to which are added those who are cared for by the family and are undiagnosed. Romania, with an increasingly aging population, risks becoming a huge reserve of people without memory, to which are added those suffering from other forms of dementia. In 2012, in Romania, there were 270,304 people with dementia. This represents 1.26% of the total population of 21,387,517. The number of people with dementia as a percentage of the population is slightly lower than the EU average of 1.55%.

Based on all these data, with the increase in the elderly population, the number of Alzheimer's patients is also increasing. For this reason, the need for day living houses is increasing.

16.2. The Situation at National Level in Italy: National Plan for Dementia

In Italy, different types of health and social-health services are available for people with cognitive disorders and dementias. In agreement with the Ministry of Health, the Istituto Superiore di Sanità (ISS) conducted a national census of all the health and social health services (public and / or affiliated or contracted) dedicated to dementia [*6*], which also involved the regional representatives for dementia and the regional health directorates, for the identification of services.

The health and social health services for dementia surveyed are:

- Centers for Cognitive Disorders and Dementias (CDCD),
- Day Centers / Integrated Day Centers
- Residential Facilities

At the basis of the approval of the Agreement in the Unified Conference of the document "National Plan for Dementia-Strategies for the promotion and the improvement of the quality and appropriateness of care interventions in the dementia sector " [*7*] there had been a profound reflection on the taking in charge of the chronic neurodegenerative patient and his family with the vision of achieving uniformity on the national territory of the taking into load.

The National Plan for Dementia was approved on 30th October 2014 by the national government in close cooperation with the Italian regions and the autonomous regions on the Italian country. It focuses its attention on the measures of the public health systems so as to: promote appropriate interventions; contrast social stigma; guarantee the rights of patients and coordinate activities, aimed at the correct integrated management of dementia.

The aim of this National Plan is to assist dementia patients and offer them quality and appropriate care interventions. In particular, its objectives are [*8*]:

- Health and social interventions and measure: this objective entails to raise awareness among citizens and people affected by dementia on the prevention measures, diagnosis and care assistance. Moreover, it entails also to achieve, through research support, progress in the care and improvement of the quality of life of people with dementia and their families.
- Strengthening the network of integrated services based on an integrated approach.

- Promoting prevention and timely diagnosis also to reduce discrimination, fostering adequate intersectoral policies. The National Plan objective pays particular attention to social inequalities and conditions of socio-health fragility and vulnerability.
- Improving the SSN (National Health Service) activities and monitoring its services through strategies and working methods based on the appropriateness of the services provided.
- Improving care assistance in the residential and semi-residential facilities.
- Reducing the stigma of the disease so as to improve the life of patients and to promote their social integration in society.
- Supporting dementia patients and their families by giving them information on the disease and on the services available.

Futhermore, the Istituto Superiore di Sanità with the financing of the Ministry of Health is implementing activities following this approach which are published on the website ***Osservatorio demenze***.

And although this is an excellent example of the political will to adapt the legislation to make taking charge of the entire national territory equal and homogeneous, to date only a part of the regions has implemented the document with its own resolution. The implementation of the Dementia Plan at a national level first of all provided for the reorganization of the clinical-assistance network for dementias through the creation and development of Centers for Cognitive Disorders and for Dementia (CDCD) in order to ensure continuity of care and appropriateness of taking charge of the person with dementia and his family in the logic of continuity and hospital-territory circularity. Until 2014, the diagnosis and prescription of drug therapy was carried out by the Alzheimer's Assessment Units (UVA), specialist outpatient clinics mostly present in hospitals and healthcare companies but often not connected to other services; the requalification and reorganization desired by the Dementia Plan was aimed at guaranteeing the creation of an integrated system of timely care and continuity of care for the person with dementia in light of the continuous and sudden changes that the disease brings with it without forgetting the support that the family requires.

The CDCD, in fact, should represent a central clinic that coordinates and supervises the activity of other clinics and services, identifying itself as a coordination center for all those involved in various title in the process of caring for the person and his family. Precisely for this reason, a multidisciplinary working group made up of various specialists and professional figures operates within the clinics, working according to shared protocols.

Unfortunately, we can say that, six years after the approval of the Dementia Plan, what was supposed to be the coordination center for the personal care process still has significant inhomogeneities and shortcomings in the organization in the various territories.

From research carried out on the national territory by the Istituto Superiore di Sanità (ISS), one out of five CDCDs is open only one day a week, about 23% of these facilities have waiting times equal to or greater than 3 months and 30% of them still use a paper archive. In addition to this, it is estimated that the number of Day Centers and Residential Facilities dedicated to dementias in the South and on the islands is lacking. From the statements of dr. Vanacore, researcher at the ISS, the organizational and structural difficulties of the system for taking care of the person with dementia emerge: "The CDCDs in charge of diagnosis and treatment are present throughout the territory national but a criticality is represented by the fact that the waiting lists are, for 2/3 of the structures, longer than a month, while the day centers for semi-residential care as well as residential structures are more present in the North.

If on the one hand we therefore have a photograph that allows us to plan the services according to the needs of the territory as well as defined by the National Dementia Plan, on the other hand, unfortunately, this programming remains firm because more and more are interventions by the family and private assistance in the face of a continuous reduction in public care services.

In the panorama of Italian welfare, the spaces in which a person with dementia can be continuously cared for are listed in three types: your home (or the home of your family member), the day center and the protected nucleus in the nursing homes. It is therefore evident that this imbalance between the increase in needs and the reduction in supply continues to have an important impact on the role of informal care and on the economic commitment of families.

In particular, in this historical period, in which the SARS-CoV-2 pandemic is affecting the most fragile layers of our society, we observe not only the discrepancy between need and supply, but also a consistent lack of operational indications to operators and caregivers. For this reason, an official document of the Istituto Superiore di Sanità was published: “Interim indications for appropriate support for people with dementia in the current scenario of the COVID-119 pandemic “ [*9*].

16.2.1. Centers for Cognitive Disorders and Dementias (CDCD)

CDCD are services responsible for the evaluation, diagnosis and treatment of cognitive disorders and dementias. Included are the recipient Services of AIFA Note 85, established within the CRONOS Project as Alzheimer UVA Evaluation Units and which, within the National Dementia Plan, are commonly referred to nationally as CDCD. The list also includes services / clinics in functional connection with a main CDCD, through delegations or relocated organizational structures of the main Service (commonly referred to as sub-UVA).

16.2.2 Day Centers / Integrated Day Centers

Day Centers or Integrated Day Centers are semi-residential, public and / or affiliated or contracted social and health structures that welcome people with dementia. These structures offer help to people diagnosed with dementia, in particular Alzheimer, and support their families.

Alzal house based in Lamezia Terme (RM) is an example of day center that offers health and social assistance through its services and activities.

The wide range of activities offered by this center encourage the participation of people from all age groups. The project fosters effective intergenerational communication and narrows the generation gap, whilst ensuring stronger integration of people with dementia in the community. Among the activities implemented, Alzal house tries to help patients reminding significant moments of their life, supporting non-verbal communication, and stimulating guests through the care of small pets (dogs, fish, birds, etc.).

However, Alzal house is only an example of many other Day Centers set up in Italy. Indeed, the Dementia Observatory of the Istituto Superiore di Sanità makes available on its website a map with a list of centers in Italy which dementia patients and their families can address to for information and help [10].

16.2.3 Residential Facilities

Residential facilities or contracted health and social health facilities welcome elderly people who are difficult to care for at home, usually because they have very specific clinical requests or require uninterrupted care, which is difficult for family members to provide. In many Residential facilities, there are Alzheimer's nuclei, specific for people suffering from forms of dementia [11]. The Alzheimer's Nuclei are areas of care and assistance for patients suffering from dementia and presenting with behavioral disorders. These areas are specifically designed for Alzheimer's patients in order to guarantee protection and safety, combined with a program of activities aimed at stimulating and maintaining the patient's cognitive functions, even with the aid of non-pharmacological therapies.

In the Alzheimer's Nucleus, the patient, self-sufficient or non-self-sufficient, can freely use all the services available in a totally safe way, since he or she can move between the common areas and his own room but always under the close supervision of the operators.

In order to mention an example, among other many residential facilities based in various Italian regions, there is the Refuge Re Carlo Alberto in Turin.

This Refuge has been providing services for older people since 2000, including people with dementia. Services include residential, day centers and home help for people with dementia and an Alzheimer's Cafe. Members of the public not directly affected by dementia are invited into a cinema on the premises to integrate the local community and people with dementia. These are involved in activities at summer camps for children, a second-hand clothes shop for the local area, everyday activities offered in the neighbourhood (markets, local festivals, restaurants, cafe's), awareness-raising activities (conferences, seminars, films) and meetings between residents and the city council so that citizens and politicians can get together and have discussions. "Dementia structures and services [are presented] in a new way, as normal part of daily life in the area, [promoting] activities not necessarily linked to conditions related to the disease – to create contexts where the illness can be discussed and to spread a concept of sharing amongst all citizens without excluding people." The Refuge received important international recognition by winning the „EFID AWARD 2014", announced by a group of European foundations and aimed at innovative projects with the aim of improving the quality of life of the elderly with dementia and, in particular, with Alzheimer [12].

16.2.4. The Patchy Situation at Regional Level

What is missing is a network that, following the diagnosis, can guide families towards activities, services, institutions that can offer support, support and assistance. Therefore, to remedy as much as possible the gaps in the projects available only in certain situations, the Diagnostic Therapeutic Assistance Pathways (PDTA) arise, i.e. organized and pre-established paths, for taking charge of the person with dementia and his family from the first signs and for the entire duration of the disease providing information, care and adequate House assistance. Even with a National Dementia Plan, the lack of uniqueness of the assistance and support procedures risks becoming a problem, not only due to the multiple diversity existing at the organizational level, but also as regards the services offered. It is therefore indispensable in a path of treatment and assistance for a disease thus disabling, the creation of a system that is flexible and integrated, able to respond promptly and in an articulated manner by integrating the therapeutic, care and support needs of people with dementia and their families.

16.2.5. Criticalities and the Role of Families

Even just from a quick overview of the major criticalities that the literature finds, we can obtain what is reported in Table 16.1.

What emerges, still completely informal and with little scientific data to support, but even more supported by this period of closure of services and blocking of access to residences, due to the COVID-19 pandemic, is that the family does not give up to take action to ensure care and affection for their relative. The resulting request for help concerns, in addition to administration adequate specific care, including strong support for family activities (even of a temporary nature), the reconciliation of different times (work-care), temporary relief, training and the need for greater communication between operators and family members.

Table 16.1.

- Family-work reconciliation, especially for the assistance of the elderly, is entirely organized and supported by families, and in particular by women, through multiple forms (grandparents, part-time parents, female renunciation of work, etc.)
- In Italy, the level of coverage of non self-sufficiency by public services is much lower than in most Western European countries. A large proportion of non self-sufficient elderly people are not in charge of public services and are supported mainly by informal personal caregivers
- The social and health expenditure is progressively decreasing; on the contrary, one component of the growing social-health welfare is the “out of pocket” health care, the one that citizens pay for out of their own pockets. These are various types of expenses: from drugs to specialist visits. According to recent studies, it seems that access to the services of a hospital often occurs only after the paid specialist visit: “in essence, you pay for access to the system, then continue for free in the public perimeter”

16.2.6. The Role of Associations, the Example of the Alzheimer Italy Federation

For more than 25 years, the Alzheimer Italy Federation, based in Milan, has been trying to respond to these requests, the largest national non-profit organization dedicated to promoting medical and scientific research on the causes, treatment and assistance for dementias, to support and support for people with dementia and their family members and the protection of their rights. Formed mainly by family members of people with dementia, brings together coordinates 46 associations that deal with dementia, and aims to create a national network of help for people with dementia and their families. It offers a dedicated national help line (02.809767) and an email address (***info@alzheimer.it***) where patients and families can ask for the services provided and information. Moreover, a new service is provided through a database (***https://bit.ly/3bYuON5***) that helps parents and families in finding facilities which offer care and assistance to dementia patients.

In addition to the national help line and the email provided, the Federation also offers various services to support people suffering from Alzheimer as:

- Consultations free of charge to help families in assisting dementia patients.
- Agreements with Equitalia (the Italian Revenue Agency) to respond to the difficulties that relatives often face in taking over the economic situation related to the disease.
- Training courses for volunteers, doctors, nurses and healthcare operators.
- Dissemination and information materials about the disease and how to help patients.

Among the many services and consultancy initiated and provided over the years, a winning answer can be said to be represented by the Community Friend of People with Dementia project, launched for the first time in Italy in 2016, and which today has 28 communities. It is in fact an example of a social initiative based on the collaboration of several subjects from the same city (institutions, associations, professional categories) engaged in the establishment of a network of aware citizens who know how to relate to the person with dementia. to make her feel at ease in the community.

In fact, as outlined by the indications present in the Global Action Plan for Dementia 2017-2025 drawn up by WHO, the, need for greater awareness in the communities is one of the actions to be taken to be able to address the phenomenon of the increasing incidence of neurocognitive disorders. Starting from the assumption that it is necessary to create a network that knows how to listen, evaluate and implement concrete inclusion strategies for the person with dementia, what the Friendly Communities of people with dementia propose to do is precisely the initiation of a process of social and cultural change that from shopkeepers to law enforcement agencies, from specialized operators to associations, from volunteers to communities built around places of worship, from students to the entire population, create a dense network of aware citizens who know how to relate to people with dementia to make them participate and make them feel at ease in the community. This new culture is useful and a reference for the citizen, but also for the general practitioner who can take advantage of the widespread knowledge of the resources available in the area in which he operates as mentioned in the key message box.

16.2.7. Other Main Associations

Besides the Federation based in Milan, on national level there are many private associations and NPOs (non-profit organisations), based in every Italian region, which operates in synergy with the National Health Service and the international organisation. They help patients affected by Alzheimer and their families at regional level. In the following paragraphs are mentioned a few, however, others can be easily found on the Internet.

16.2.7.1. AIMA: Italian Association for Alzheimer Disease

The Italian Association for Alzheimer Disease (AIMA) is a non-profit organisation made up of 24 other associations, 15 listening centers and operational groups that work in many Italian regions (including the Toscana Region; Emilia Romagna Region; Campania Region). The association’s mission is help and support dementia patients and their families through services such as a help line which is different for each region and training course for families and caregivers. Among the services provided for supporting patients, the association organises “Coffee meeting” which was born as a meeting space, within a commonly frequented Social Center or Club, designed for people with dementia and their families. The meeting takes place on a set date, in a peaceful and welcoming environment where dementia patients, family members and volunteers, with the guidance of an expert, can drink coffee, listen to music, play cards, dance or eat something together. However, it is above all a place of aggregation, of recovery and of socialization by family members and people with dementia to stimulate their skills and their abilities. Indeed, there are positive effects both for the person with dementia, in terms of improvement of behavioral disorders, and for his family, with a decrease in psychological burden. It is of great help to the family member to know people with whom to share their experience and from whom to get practical advice and information.

Furthermore, the non-profit organisation works at two main levels: internal and external. At internal level, AIMA coordinates the campaigns of the association and supports the activities carried out in the territorial centers. On the other hand, at external level it aims to raise awareness of the disease among the citizens through campaigns of dissemination. Moreover, the organisation affects the welfare policies by monitoring regional and national legal activities together with other main associations which fight for the protection of patient's rights.

16.2.7.2. Alzheimer Uniti Italia Onlus

Alzheimer Uniti Italia Onlus is a national voluntary association which has various branches in many Italian regions. The Association pursues objectives of social solidarity towards people suffering from Alzheimer's disease, and other type of dementia, as well as their family members, in particular, through:

- interventions aimed at supporting people and their families.
- Assistance of people and their families in relations with health centers, public bodies.
- Raising awareness of the particular problems that Alzheimer's disease raises and supporting patients and their families.
- Study and promotion of specific assistance models.
- Training of specialized personnel also through the organization of conferences and courses.
- Wide-ranging interventions for the protection of the dignity and rights of individuals and families.

The association has also been offering an online form (***https://bit.ly/3Hewdh1***) through which families or patients can ask for information and questions to therapists, social assistants, physiotherapists, psychologist, legal counsels and accountants.

16.2.7.3. Manuli Foundation

Manuli Foundation, based in Milan and set up in 1992, is an association whose aim is to tangibly support Alzheimer patients and their families. It helps dementia patients in an efficient and an effective way with its services and, in particular, with its caregiver help services. Furthermore, the foundation confronts itself every day with Hospitals, Alzheimer's Assessment Centers, Integrated Day Centers, Municipality and Rehabilitation Institutes. This has allowed Manuli Foundation to stipulate agreements with these bodies specialized in Alzheimer disease, aimed at facilitate access to services in favor of the assisted persons of the Manuli Foundation. In addition, the Foundation supports with its expertise those entities that require the support of competences and experience to start new activities in the field of care for Alzheimer's patients.

Since the Covid-19 has spread throughout Italy, the services have been offered at the patient's home, in compliance with the procedures for containing the virus, through assistance free of charge with specialized personnel and after an interview with the psychologist for the taking charge and activation of each individual case.

From 2021, an important increase in assistance is expected through online activities with useful videos with advice and support from psychologists and experts for the management of the Alzheimer's patient, specialist consultations and the possibility of accessing platforms whose multimedia contents serve as support for caretaker. Furthermore, in collaboration with social workers, neurologists, geriatricians, psychologists, occupational therapists, physiotherapists and nurses, the Foundation raises awareness among its public. It guarantees the supervision and monitoring of the work of volunteers and operators, so that they can provide quality assistance, thanks to regular video conferences scheduled by the team.

16.3. The situation at national level in Turkiye

The care and supervision of Alzheimer's patients is a challenging process for their relatives. Relatives of patients need support if the care and surveillance of patients is done at home. There are some institutions for the short-term and long-term care and surveillance of patient relatives. Among these institutions, there are organizations that offer some free services, as well as institutions that provide paid care. In this context, some institutions for Alzheimer's patients in our country will be mentioned. Below is some information about the association, day-care centres, nursing homes and elderly care centers in Turkiye for Alzheimer's patients.

16.3.1. Alzheimer's Association of Turkiye

The Alzheimer's Association of Turkiye focuses on raising awareness and education of the public in its work. The Alzheimer's Association of Turkiye, which was established in 1997 by the relatives of patients and provides service with 14 branches throughout Turkiye, supports Alzheimer's patients and their relatives with the support of specialist physicians and volunteers. The provinces where the Alzheimer's Associations of Turkiye are located are as follows: Istanbul headquarters, Adana, Antalya, Ankara, Bursa, Denizli, Eskişehir, İzmir, Kadıköy, Kayseri, Karabük, Mersin, Konya, Samsun.

The Alzheimer's Association of Turkiye has a website that offers extensive information, as well as the services it provides with its branches in the provinces. On this site, relatives of patients can access necessary information for the care and supervision of their patients (***https://www.alzheimerdernegi.org.tr/***).

16.3.2. Day care centers

Below are the day life centers established under the leadership of some metropolitan and district municipalities and some other associations with the contributions of the Alzheimer's Association of Turkiye. These centres offer services that Alzheimer's patients and their relatives can benefit from. Daycare houses have been commissioned:

- To inform patient relatives about care;
- To bring relatives of patients together with experts in their fields;
- To provide the relatives of the patients with some time and relaxation while doing this difficult task;
- To increase solidarity among patients' relatives;
- To make our Alzheimer's patients have a pleasant and quality time;
- To enable our Alzheimer's patients to participate in social life;
- To slow the course of the disease with the rehabilitation services required by the diseases;
- To increase the quality of life of patients and their relatives;
- To extend the hand of an expert friend needed by patients and their relatives.

Alzheimer’s Daycare House:

It was established by the Alzheimer’s Association of Turkiye with the sponsorship of Şişli Municipality. Alzheimer’s Association Daycare House is to provide **free of charge** services and care to the guests and their relatives, in compliance with human rights and ethical rules, at a high level of satisfaction and at international standards. Daycare House, which will provide Alzheimer’s patients to spend pleasant and quality time, still provides service 5 days a week and free of charge. In addition to general activities such as reading the newspaper, reading poetry, making a monthly calendar, cooking, reading calendar sheets, writing story-mania, tying shoes, traffic signs, turning a pinwheel, decorating, playing mikado, playing backgammon, dancing, solving puzzles, Mental Activities, Psycho-motor Activities, Physical Exercises, Art Activities, Special Day Celebrations: Travel Programs, and Information and Psychotherapy Meetings are organized.

Adress: Mecidiyeköy, Kuştepe Mah, Korkoyuncu Sok No:57, 34384 İstanbul.

Tel: (0212) 224 41 89

Nazilli Meeting and Counseling Centre for Alzheimer’s Patients and Their Families

Meetings and counseling are held at the center for Alzheimer’s patients and their families.

Adress: Sümer Mah. Hürriyet Cad. 463/2 Nazilli, Aydın

Tel: 0256 314 00 80

Izmir Metropolitan Municipality Alzheimer’s and Dementia Centre

Meeting and Solidarity Centre for Alzheimer’s and Dementia Patients and Their Families brings together the elders with Alzheimer’s (1st stage) and mild dementia, who can perform their daily living activities, and who do not have any illness that prevents them from meeting their own needs in body functions. The elders who benefit from the center engage in activities that strengthen memory and engage in activities accompanied by specialist doctors, nurses, and trainers.

Adress: İnönü Cad. No:817 Kat: 1 Üçkuyular - Karabağlar / İZMİR

Tel: 0232 285 07 79

Website:https://www.izmir.bel.tr/tr/AlzheimerVeDemansHastaVeAileleriBulusmaDanismaMerkezi

Eskişehir Tepebaşı Alzheimer's Guest House:

There is also a greenhouse, hobby garden, sports units and physiotherapy center in the Yaşam Village, where Alzheimer's, disabled, and elderly guest houses are also located. The facility provides daycare and boarding care services under the control of Alzheimer's Association. It was put into service with the cooperation of Eskişehir Tepebaşı Municipality, Lions Association, and Alzheimer's Association. It aims to facilitate the lives of our citizens with Alzheimer's disease and their families, and to support their participation in social life. Alzheimer's Guesthouses continues to provide boarding services with a total of 5 guesthouses and 101 beds. 20 of our citizens with Alzheimer's disease benefit from our Day Care Service free of charge two days a week.

Address: Tepebaşı Belediyesi Alzheimer Konukevlerimiz, Tepebaşı bölgesi Aşağısöğütönü Mah..

Tel*: 0 222 314 07 56*

Website:*https://www.tepebasi.bel.tr/disbirimlerdetay.asp?hid=101*

Kadıköy Alzheimer's Daycare Centre and Social Life Centre:

It is to connect the 1st and 2nd stage Alzheimer's patients residing in Kadıköy to life, to give life energy, to enable them to enjoy their daily life activities, to delay the stage of the disease with mental and psycho-motor rehabilitation works, and to increase the social functionality of the person. It also provides trainings, socio-cultural activities, psychological support programs (individual or group), well-being programs, etc. to the relatives of the patients.

Adress: 19 Mayıs Mahallesi, Sultan Sokağı No:29, 34736 Kadıköy/İstanbul --

Tel: (0216) 356 11 15

alzheimer@kadikoy.bel.tr

Adress: Tepegöz Sokak, Nural Köşkü No:43 Göztepe, Kadıköy/İstanbul, (0216) 350 75 79

Mersin Elderly Life Centre / Mersin Private Dementia-Alzheimer's Disabled Care Centre

It was built to facilitate the lives of all elderly people, to ensure their socialization, and to reduce the burden of their relatives. The aim of the center, which was established under the leadership of the Mersin

Branch of the Alzheimer's Association of Turkiye, is to raise awareness in the society regarding Alzheimer's disease and to support the relatives of the patients. The association has carried out many projects for this purpose. The most important among these projects is the "Elderly Life Centre" Project, which was built entirely with donations to provide day or continuous care services to Dementia/Alzheimer's patients and to reduce the care burden of patient relatives. It provides daycare and boarding care services under the control of Mersin Alzheimer's Association. Counseling and rehabilitation services are provided to 20 Alzheimer's patients and their relatives a day.

Adress: 50. Yıl, 15. Cd. No:27, 33150 Yenişehir/Mersin

Tel: (0324) 332 00 05

Konya Karatay Municipality / Elderly Care-Education Practice and Alzheimer's Life Centre:

Konya Alzheimer's Day Life Centre was established in Karatay, one of the central districts of Konya, under the leadership of Alzheimer's Association of Turkiye Konya Branch Office, with the protocol signed jointly by Karatay Municipality, Necmettin Erbakan University, and Konya Provincial Health Directorate. It provides great support to patients and their relatives for Alzheimer's. The aim of the centre, which provides service between 09.00 and 17.00 on weekdays, is to ensure that Alzheimer's patients are self-sufficient during the disease process, to increase their social functionality, and to support their physical, social, psychological, and self-care needs. At the same time, it is to relieve the person and people who take care of the patient during the Alzheimer's disease process.

Adress: Fevziçakmak, Cevher Dudayev Cd. No:87, 42050 Horozluhan Osb/Karatay/Konya

Tel: (0332) 350 59 69

Antalya Blue House – Meeting Centre for Alzheimer's Patients and Relatives

The Centre is designed as a common area for patients and their relatives, where Alzheimer's patients can improve their daily activities, lead an active life, protect their existing reserves, and meet for families and exchange information together. Within the scope of the project, family members who provide home care under the name of Dementia Mobile Service are also reached. In this way, families who are in remote areas that cannot reach the center and therefore have a disadvantage are provided with services at home, and they are provided with the service of Alzheimer's Patients and Relatives of Patients Meeting Centre. Under the name of Blue House Talks, seminars are held for patients' relatives and open to the public. The Centre carries out its activities with the contributions of Antalya Metropolitan Municipality.

Address: Arapsuyu, Atatürk Blv., 07070 Konyaaltı/Antalya
Phone Number: (0242) 230 10 09
Website : http://maviev.antalya.bel.tr/

Manisa Alaşehir Alzheimer's Counseling Center

Alaşehir Municipality, which was put into service with the support of Manisa Metropolitan Municipality, serves as a Free Alzheimer's Disease Counseling Centre. In addition to the free rehabilitation service provided to those at every stage of the disease, the Counseling Centre helps patients' relatives to continue their social lives actively and to breathe a little, with education, counseling, awareness-raising, and social and psychological support. Patients who are treated at the center are taken from their homes in the morning and left in the evening with the transportation service from their homes. Gerontologists, nurses, psychologists, sociologists, and patient care personnel work in the Alzheimer's Centre, which has rest rooms and a cafeteria, where patients are supported with morning exercises, intelligence-enhancing games and many activities. Relatives of patients who want to receive service from the free consultation center can come to the center and apply with a petition.

Nursing Homes

Nursing homes are institutions that provide care for the elderly in a healthy environment, lead a peaceful life, and actively participate in social life. Institutions have two different configurations as public and private nursing homes. Public nursing houses are affiliated with municipalities and the Ministry of Family and Labour. While private nursing homes have a similar service structure to public nursing homes, the opportunities provided, application and admission process, and fees may differ from public nursing homes.

You can learn about the features and admission requirements of nursing homes from the link below.

https://www.mevzuat.gov.tr/mevzuat

For the list of nursing homes in your province, you can visit the Ministry of Family and Social Services: https://www.ailevecalisma.gov.tr/media/6114/3-oezel-huzurevleri.xlsx

https://www.alzheimerdernegi.org.tr/huzurevi-ve-bakimevi-bilgilendirme-rehberi-2021/

Municipal Nursing Homes

Especially metropolitan municipalities and some of the district municipalities operate in terms of Municipal Nursing Home, Elderly Nursing Home, Municipal Patient Nursing Home, Municipal Alzheimer's Nursing Home, Municipal Boarding Physical Therapy Services. These nursing homes are located in the provinces of Ankara, Istanbul, Izmir, Antalya, Bursa, Kayseri, Muğla, Samsun, Burdur, Balikesir, and Denizli.

Special Disability Care Centres

A total of 295 special disabled care centres located in almost every province of Turkiye are those that care and supervise Alzheimer's patients. These centres are paid. In addition, A-Dora Nursing Homes-Special care units are an institution operating on behalf of the Alzheimer's Foundation and serve with its Dragos and Ataşehir branches.

Private Nursing Home and Nursing Home Elderly Care Centres

There are 267 private nursing homes and nursing home elderly care centers operating in various provinces of Turkiye. These centers are paid. Anyone aged 55 and over can stay in a private nursing home, as long as they do not have a physical and psychological disorder or substance addiction that will harm their environment. Anyone from the advanced age group who needs institutional care both medically and socially can stay in private nursing homes for as long as they want and as long as they meet the necessary conditions.

The addresses of the provinces and centres where these centres are located are available on the website of the Ministry of Family and Social Services, General Directorate of Disabled and Elderly Services.

(https://www.aile.gov.tr/eyhgm/kuruluslar/yasli/).

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ANNEX 1

International Convention dated 13.05.2009: Article 1, Article 19, and Article 26

***Article 1 - Aim -** The aim of this Convention is to promote and ensure the full and equal enjoyment of all human rights and fundamental freedoms by persons with disabilities and to strengthen respect for their human dignity.*

The concept of disability includes persons with long-term physical, mental, intellectual, or perceptual impairments that hinder their full and effective participation in society on an equal basis with other individuals.

***Article 19 Ability to Live Independently and Inclusion in Society-** The States which are Parties to this Convention recognize that all persons with disabilities have the right to live in society under equal conditions with other individuals, and take the necessary measures effectively to facilitate their full participation in society and to fully enjoy this right. Within this framework, the following points should be noted:*

(a) Persons with disabilities have the right to choose their residence, where and with whom they will live, on an equal basis with others, and cannot be forced into a special arrangement;

(b) Persons with disabilities should be provided with access to the in-house and other community support services they need to live and be included in the community, including personal support, and the isolation and segregation of people with disabilities should be prevented;

(c) Public services and facilities should be open to persons with disabilities on an equal basis with others and be responsive to their needs.

Article 26 Habilitation and Rehabilitation -

1. States which are Parties to the Convention shall effectively take appropriate measures, including peer support, to ensure that persons with disabilities achieve maximum independence, achieve their full physical, mental, social and occupational abilities and participate fully in all aspects of life. In this regard, they provide comprehensive habilitation and rehabilitation services, particularly in the fields of health, employment, education and social services, and strengthen and expand existing services. For this, they should follow a path like this:

a) Habilitation and rehabilitation services and programs should begin as early as possible and be based on a multidisciplinary assessment of individuals' needs and strengths;

b) Participating in habilitation and rehabilitation services and programs that support the inclusion and social integration of people with disabilities should be based on consent, and these services and programs should be offered as close as possible to places where people with disabilities live, including in rural areas.

2. States which are Parties to the Convention shall support the development of basic and continuing education programs for professionals and staff working in habilitation and rehabilitation services.

3. They shall promote the accessibility, knowledge, and use of assistive devices and technologies for persons with disabilities related to habilitation[1] *and rehabilitation*[2]*.*

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[1] ***Habilitation*** *is a concept specific to people with disabilities. The services which are aimed at providing physical, social, mental, and professional skills that have the purpose to meet the individual and social needs of the disabled and enable them to continue their lives independently are called habilitation.*

[2] ***Rehabilitation*** *is the treatment, care, and training work applied to eliminate a person's disability or illness that prevents him from doing business, and to bring him or her into a working condition.*

ANNEX 2

The Turkish Civil Code for Those With Alzheimer's and Similar Disabilities

1) Legal capacity

Article 8 - Every person has a legal capacity. Accordingly, all people are equal in being competent in rights and obligations within the limits of the legal order.

2) Juridical capacity

1. Scope

Article 9 - *A person who has the capacity to act can acquire rights and become indebted by his/her own actions.*

2. Terms

a. In general

Article 10 - *Every adult person who has the power to distinguish and is not limited has the capacity to act.*

d. Ability to distinguish.

Article 13 - *Anyone who is not incapable of acting rationally because of his or her age or mental illness, mental weakness, drunkenness or similar reasons has the power to distinguish in accordance with this Law.*

3. Incapacity to act

1. In general

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Article 14 - *Those who do not have the po3wer to discriminate, minors, and people with disabilities do not have the capacity to act.*[3]

2. Disability of power to distinguish

Article 15 - *The acts of a person who does not have the power to distinguish, without prejudice to the discrete situations indicated in the law, do not have legal consequences.*[4]

3. Minors and the limited with the power to distinguish

Article 16 - *Minors and persons with the power to distinguish cannot enter into debt by their own actions, without the consent of their legal representatives. This consent is not necessary in gaining gratuitous and exercising strictly personal rights.*[5]

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[3] Having a right is not the same thing as being able to do what is necessary. The “inviolable, inalienable, and indispensable fundamental rights and freedoms” guaranteed by the Constitution can only be exercised by “fully competent” individuals who “have the power to discriminate”. Individuals who have partially or completely lost this ability are granted these rights within the framework of special protection rules. Those who do not have the power to discriminate are expressed as fully incompetent. Those who have the power to discriminate partially are defined as limited incompetence.

The ability of a person to act in a rational way and to grasp the causes and consequences of his/her behavior correctly is called the power of discrimination.

In the first stage of dementia, the patient has not yet permanently lost his/her power of discrimination. While its accuracy is debatable, it is not yet considered to be placed under guardianship at this stage. Appointment of legal counsel to patients in the initial state may be considered. The application seems insufficient. This is because the degree of the disease requires very good observation. In case that any risk factor becomes a reality, serious problems may occur due to late intervention. The patient may cause situations that will endanger himself/herself or others and leave him/her in a difficult situation, and situations that are difficult or impossible to solve may arise. Also, the legal counsel does not have the opportunities and powers that the guardian has even if the situation is noticed in time. In order to eliminate these drawbacks, we think that the appointment of a guardian in the first stage of dementia is appropriate [1].

[4] In limited incompetent persons, it is possible for the transaction to become valid by giving a license later, depending on the nature of the transaction. Fully incompetent persons cannot perform any legal action on their own, except for the exceptions specified in the law, it is done by the legal representative on their behalf. It is out of question for the transaction m..ade b....y the incompetent to be validated by giving permission later. However, in cases where there is no need for a declaration of will, the actions of incompetent persons have legal consequences.

[5] Minors and persons with the power to distinguish are liable for their wrongful acts. In case of limited incompetence, incompetence is the main and competence is the exception. These exceptions are those listed in Article 16 above. Again, in case that asserting the invalidity of a legal act carried out by a person who lacks the power to distinguish means abuse of right in terms of Article 2 of the TMK (Turkish Civil Code), it will result in provisions as if the transaction in question was valid. As stated in the Supreme Court Judgment Unification Decision dated 09.03.1955 and numbered 22/2, if the person who is not able to appeal had the power to appeal, he would act in the same way and if even a person with normal intelligence could treat him

Guardianship/guardianship order/guardianship bodies

A. In general.

Article 396 - *Guardianship bodies are guardianship offices, guardians, and trustees.*

B. Guardianship offices

1. Public guardianship

Article 397 - *Public guardianship is carried out by guardianship offices consisting of guardianship authority and supervisory authority. The guardianship authority is the magistrate's court and the supervisory authority is the civil court of first instance.*

Guardian and trustee

Article 403 - *The guardian is obliged to protect all the interests of the minor or restricted person under guardianship regarding his personality and assets and to represent him/her in legal proceedings.*

A trustee is appointed to do certain jobs or manage assets. The provisions of this Law on the guardian shall also apply to the trustee unless otherwise stated.

Conditions that require guardianship

Limitations

Mental illness or mental weakness **Article 405 -** *Any adult who cannot work due to mental illness or mental weakness, or who needs constant help for his/her protection and care, or who jeopardizes the safety of others, is restricted.*

Administrative authorities, notaries, and courts, who learn of the existence of a situation that makes it necessary to be placed under guardianship while performing their duties, must immediately notify the competent guardianship authority.

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in the same way, he should not be able to claim the invalidity of the treatment by mentioning that he is incapable. In the case subject to the decision, the cancellation of the mortgage based on the claim of lack of legal capacity has been requested. The person, who established the mortgage in favor of the bank, with the report he received after the mortgage facility, claims that he had a mental illness at the date of the incident, therefore the mortgage facility he made was invalid and he would not be liable for the debt. However, the process will work in the same way for a person with normal intelligence. A loan was taken and a mortgage was established in return. The validation of the transaction will not harm the restricted person and will cause other injustices.

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IV. On request

Article 408 - Any adult who proves that he/she cannot manage his/her work properly due to his/her old age, disability, inexperience or serious illness may request restraint.

Appointment of guardian

A. Conditions

1. In general

Article 413 - *The guardianship authority appoints an adult who is capable of performing this duty as a guardian.*

2. The priority of the spouse and relatives

Article 414 - *Unless legi. ti.mate reasons prevent it, the guardianship authority appoints the spouse or one of the close relatives of the person to be placed under guardianship, provided that they have guardianship conditions. In this appointment, the proximity of the settlements and personal relationships are taken into account.*

3. The request of those concerned

Article 415 - *Unless legitimate reasons prevent the guardianship, the person to be placed under guardianship or the person indicated by his/her mother or father is appointed.*

4. Obligation to accept guardianship

Article 416 - *Those who are appointed as guardians from the residents of the person under guardianship are obliged to accept this duty.*

5. Reasons for avoiding guardianship

Article 417- *The following persons may not accept as guardians:*

1. Those who have completed the age of sixty,

2. Those who can hardly do this job due to their physical disabilities or permanent illnesses,

3. Parents of more than four children,

4. Those who have guardianship duties on them,

5. President, members of the Turkish Grand National Assembly, vice-presidents, ministers, judges and prosecutors.

Trusteeship and legal advice

A. Situations that require trusteeship

I. Representation

Article 426 - *The guardianship authority appoints a trustee for representation upon the request of the person concerned or ex officio in the following cases or in other cases specified in the law:*

1. If an adult is not able to perform an urgent job himself/herself or to appoint a representative due to illness, being in another place or similar reasons,

2. If the interests of the legal representative and the interests of the minor or the restricted person conflict in a business,

3. If there is an obstacle to the performance of the legal representative's duties.

B. Legal advice

Article 429 - *A legal consultant is assigned to an adult person whose legal capacity is deemed necessary to be limited in terms of protection, although there is no sufficient reason for restriction, to get his/her opinion on the following matters:*

1. To submit a lawsuit and settle,

2. To purchase, sale, pledge of immovables and establishment of another real right on them,

3. To purchase, sale and pledge of valuable documents,

4. Construction works outside the ordinary administrative boundaries,

5. Lending and receiving,

6. Collecting the principal,

7. Remission,

8. Commitment to foreign exchange,

9. Don't be a guarantor.

Under the same conditions, a person's authority to manage his/her assets may be revoked, without prejudice to his/her right to dispose of his/her income as he/she wishes.

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D. Prosedure

Article 431 - The rules regarding the appointment of the guardian are also applied in the appointment of the trustee and legal advisor.

Limitation of freedom for the purpose of protection

A. Conditions

Article 432 - Every adult person who poses a danger to the society due to mental illness, mental weakness, alcohol or drug addiction, a serious infectious disease or vagrancy, is placed in an institution suitable for treatment, education or rehabilitation, if personal protection cannot be provided in any other way. Public officials, who learn of the existence of one of these reasons while performing their duties, must immediately notify the competent guardianship authority.

In this regard, the burden that the person brings to his/her environment is also taken into consideration.

The person concerned is discharged from the institution as soon as his/her situation allows.

D. Objection

Article 435- *The person or their relatives placed in the institution can object to the supervisory authority against the decision within ten days, starting from the notification to them.*

This right can also be used in case of rejection of the request to be discharged from the institution.

Duties of guardian

A. Inauguration

I. Bookkeeping

Article 438 - *Upon the finalization of the decision to be appointed to guardianship, the registry of the assets to be managed shall be kept without delay by the guardian and a person appointed by the guardianship authority.*

II. Storage of valuables

Article 439 - *Valuable documents, valuables, important documents and the like are placed in a safe place under the supervision of the guardianship authority, if there is no inconvenience in terms of the management of the assets.*

III. Selling movables

Article 440 - *In case that the interest of the person under guardianship requires, movables other than valuables are sold by auction in accordance with the instruction given by the guardianship authority. The judge may also decide to sell by bargaining, taking into account the special circumstances, the nature of the movable or its low value.*

Items of special value to the person under guardianship or their family cannot be sold unless it is necessary.

IV. Depositing money

1. Obligation to deposit

Article 441 - *Money that is not necessary for the person under guardianship or for the management of his/her assets is deposited in a national bank determined by the guardianship authority or converted into securities issued by the Treasury in order to generate interest.*

The guardian, who delays the deposit of the money for more than one month, is obliged to pay the loss of interest.

2. Conversion of investments

Article 442 - *Investments that are not reassuring enough are converted into safe investments.*

The conversion must be done at the appropriate time and in the best interest of the person under guardianship.

V. Commercial and industrial enterprises

Article 443- *If there is a commercial, industrial and similar enterprise in the assets of the person under guardianship, the guardianship authority gives the necessary instructions for the continuation and liquidation of their operation.*

VI. Sale of real estate

Article 444 - *The sale of immovables is made by a person to be assigned by the guardianship authority for this task, by an auction, upon the instruction of the guardianship authority, only in cases where the interest of the guardianship requires, and the tender is completed with the approval of the guardianship authority. The decision regarding the approval must be made within ten days starting from the tender day.*

However, the supervisory authority may also decide to sell by bargaining, taking into account exceptionally special circumstances and the low quality or value of the immovable.

B. Care and representation

1. Care to person

2. In incompetent

Article 447- *The guardian is obliged to protect the restricted and to approve all his/her personal affairs.*

In cases where delay is inconvenient, the guardian may place the restricted person in an institution for protection purposes, detain him/her in an institution, and immediately notify the guardianship authority of the situation.

II. Representation

1. In general

Article 448- *Provided that the provisions regarding the powers of the guardianship offices are reserved, the guardian is authorized to represent the person under guardianship in all legal proceedings. Forbidden transactions*

Article 449 - *Being a guarantor on behalf of the person under guardianship, establishing a foundation and making donations are prohibited.*

3. Obtaining the opinion of the person under guardianship

Article 450 - *If the person under guardianship has the ability to form and express their views, the guardian is obliged to take his/her opinion, as far as possible, before making a decision on important matters.*

The fact that the person under guardianship has found the job appropriate does not relieve the guardian from responsibility.

4. Works that the person under guardianship can do

a. Consent of guardian

Article 451- *The person under guardianship, who has the power to distinguish, may enter into an obligation or waive a right with the explicit or implicit consent or subsequent approval of the guardian.*

In case where the transaction is not approved within a suitable period determined by the other party or determined by the judge upon application, the other party is freed from being bound by it.

b. The result of disapproval

Article 452- *In transactions that the guardian has not approved, each of the parties may request back what he/she has given. However, the person under guardianship is only liable for the amount of enrichment spent for his/her own benefit or available in his/her assets at the time of reclaiming or the amount he/she disposed of without good faith.*

If the person under guardianship has misled the other party that he/she has the capacity to act, he/she will be liable for the damage he/she has suffered.

5. Profession or art

Article 453 - *In case where the person under guardianship is given permission to carry out a profession or art by the guardianship authority, that person is authorized to carry out all kinds of ordinary transactions related to this and is responsible with all his/her assets for such transactions.*

C. Managing assets
I. Management and accountability obligations

Article 454 - *The guardian must carefully manage the assets of the person under guardianship, like a good manager.*

The guardian is obliged to keep an account related to the administration and to present the account to his/her examination on the dates determined by the guardianship authority and in any case once a year.

Where the person under guardianship has the ability to form and express their views, they are made available to the extent possible during the examination of the account by the judge.

II. Free goods

Article 455 - *The person under guardianship freely manages and uses the goods left at his disposal and the goods he has earned by working with the permission of the guardian.*

D. Duration of the task

Article 456 - *The guardian is appointed for two years as a rule.*

The guardianship authority may extend this period for two years each time.

After four years, the guardian can exercise his/her right to abstain from guardianship.

E. Guardian's fee

Article 457 - *The guardian may request a fee to be paid from the Treasury from the assets of the person under guardianship, if not possible. The fee to be paid is determined by the guardianship authority for each accounting period, taking into account the labour required by the management and the income of the managed assets.*

Duties of Guardian Offices

A. Complaint and objection

Article 461- *The person under guardianship who has the power to discriminate and each related person can complain to the guardianship authority against the actions and transactions of the guardian.*

An objection can be made to the supervisory authority against the decisions of the guardianship authority within ten days starting from the date of notification.

B. Permission

1. From the guardianship authority

Article 462 - *The permission of the guardianship authority is required in the following cases:*

1. To purchase, sale, pledge of immovables and establishment of another real right on them,

2. Purchase, sale, transfer, and pledge of movable or other rights and values other than ordinary management and business needs,

3. Construction works that exceed the limits of ordinary management,

4. Lending and receiving,

5. Commitment to foreign exchange,

6. Making product lease agreements for one year or more and immovable rental contracts for three years or more, *7. The person under guardianship is engaged in an art or profession,*

8. In cases of urgency, without prejudice to the guardian's authority to take temporary measures, litigation, settlement, arbitration, and concordat,

9. Contracts for property regime, division of inheritance and transfer of inheritance share

10. Statement of insolvency without paying debts,

11. Making life insurance for the person under guardianship,

12. Making an apprenticeship contract,

13. Placement of the person under guardianship in an education, care, or health institution,

14. Changing the place of residence of the person under guardianship.

II. From the supervisory authority

Article 463 - *In the following cases, the permission of the supervisory authority is required after the permission of the guardianship authority:*

1. Adoption of the person under guardianship,

2. Naturalization or exit of the person under guardianship,

Acquisition or liquidation of a business, entering into a partnership requiring personal responsibility or becoming a partner in a company with significant capital,

3. Making a lifetime pension or income or care until death contracts,

4. Acceptance and rejection of the inheritance or making an inheritance contract,

5. Making the minor adult,

6. Making a contract between the person under guardianship and the guardian.

7. Examination of reports and accounts

Article 464 - *The guardianship authority examines the reports and accounts to be submitted by the guardian in certain periods. When it deems necessary, it requests their completion or correction.*

The guardianship authority accepts or rejects reports and accounts. When necessary, it takes appropriate measures to protect the interests of the person under guardianship.

D. Absence of permission

Article 465 - *Transactions performed by the guardian without obtaining the permission of the authorized guardianship offices, although required by law, are considered to be transactions made by the person under guardianship without the consent of the guardian.*

B. Responsibility of the guardian

Article 467 - *The guardian is responsible for the damage he/she caused to the person under guardianship with his/her faulty behaviour while fulfilling his/her duty.*

The same provision applies to trustees and legal advisors.

Marriage License and Obstacles

A. Conditions of the license

II. Ability to distinguish

Article 125 - *Those who do not have the power to distinguish cannot marry.*[6]

III. Permission of the legal representative

2. About the Disabled

Article 127 - *A restricted person cannot marry without the permission of his/her legal representative.*

3. Applying to court

Article 128 - *After hearing the legal representative who does not allow marriage without a justified reason, the judge may allow the minor or restricted person to marry.*[7]

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[6] *The person to be married should be able to comprehend the meaning of marriage and fulfill the responsibilities that marriage may impose on him/her. The power of discrimination is sought at the time of marriage. A person who seems to have constantly lost the power to distinguish cannot marry. People with dementia may have the power to distinguish in the early or perhaps intermediate stages of the disease. In this case, there is no harm in getting married.*

[7] This permission, of course, consists of checking whether the person who wants to

B. Marriage barriers

III. Mental disorders

Article 133 - *Mentally ill people cannot marry unless it is understood with the official health board report that there is no medical problem in their marriage.*[8]

IV. Superstitious marriages

A. Absolute nullity

I. Reasons

Article 145 - *Marriage is supersiticious with absolute nullity in the following cases:*[9]

1. One of the spouses being married at the time of marriage,

2. One of the spouses being constantly deprived of the power to distinguish for a reason during marriage,

3. One of the spouses having a mental illness that prevents marriage,

4. The existence of kinship between the spouses to prevent marriage.

Divorce

A. Reasons for divorce

V. Mental disorder

Article 165 - *In case that one of the spouses is mentally ill and therefore the joint life becomes unbearable for the other spouse, this spouse can file a divorce case, provided that it is determined by the official health board report that it is not possible for the disease to be cured.*

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marry has the power to distinguish. If required, the help of an expert will be used.

[8] *In the same way, it can be considered that official health board permission will be required for dementia patients by comparison.*

[9] *In cases where dementia is advanced, it means that there is no power to distinguish a permanent reason at the time of marriage. In this case, if the marriage has taken place in some way, the marriage is superstitious with absolute nullity. That is, it is void from the very beginning. It can be decided to nullify the marriage through a lawsuit. In other words, it does not result in a divorce, but as if the marriage never took place. For this reason, there will be no alimony, compensation, rights arising from the property regime, etc., which are ancillary to the marriage.*

ANNEX 3

The Turkish Law of Criminal Procedure

Observation, Examination, Discovery, and Autopsy

Observation

Article 74 - *(1) In order to determine whether the suspect or accused, who has strong suspicions about committing the act, is mentally ill, if he is mentally ill, how long he has been ill and the effects of this on the behavior of the person, upon the recommendation of the specialist physician, after hearing the public prosecutor and the defense counsel, it may be decided by the magistrate in the investigation phase, by the court during the prosecution phase, to be taken under observation in an official health facility.*

(2) In case that the suspect or the accused does not have an attorney, an attorney is appointed by the bar association upon the request of the judge or the court.

(3) The observation period cannot exceed three weeks. In case where it is understood that this period will not be sufficient, additional periods may be given, not exceeding three weeks each time, upon the request of the official health institution. However, the sum of the periods cannot exceed three months.

(4) An appeal can be made against the decision to be placed under surveillance. The objection suspends the execution of the decision.

(5) The provision of this Article is also applied in cases where a decision to stay the proceedings must be rendered pursuant to the eighth paragraph of Article 223.

SECOND SECTION

Termination of Public Litigation

FIRST PART

End of Hearing and Sentencing

End of Hearing and Sentencing

Article 223 – *(1) After the announcement that the hearing has ended, a verdict is given. Acquittal is the decision that there is no room for punishment, conviction, ordering a security measure, rejection of the case, and dismissal.*

(2) Acquittal;

a) *The charged act is not defined as a crime in the law,*

b) It is proven that the charged crime was not committed by the accused,

b) It is proven that the charged crime was not committed by the accused,

d) Despite the fact that the charged crime was committed by the accused, there is a reason for compliance with the law in the event,

e) It is not proven that the charged crime was committed by the accused,

The cases are decided.

3) About the accused;

a) The presence of minor age, mental illness or deaf and dumbness or temporary reasons in connection with the offense charged,

b) (Amendment: 25/5/2005 - Article 5353/30) The commission of the charged crime by fulfilling an illegal but binding order or by necessity or under the influence of force or threat,

c) Crossing the border in legitimate defense due to excitement, fear, and haste,

d) Making the mistake that eliminates the defect,

In their cases, it is decided that there is no need to impose a penalty due to the absence of fault.

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4. Despite the fact that the committed act continues to be a crime;

a) Active regret,

b) Existence of personal grounds for impunity,

c) Mutual insults,

d) the littleness of the wrongful content of the act committed,

Therefore, in cases where the perpetrator is not punished, it is decided that there is no room for punishment.

5. If it is proven that he/she has committed the charged crime, a conviction is given for the accused.

6. Where it is proven that he/she has committed the charged crime, a security measure is imposed instead of a certain punishment or in addition to the conviction. 9159

7. If there is a previous judgment or a lawsuit filed for the same defendant due to the same act, the lawsuit is dismissed.

8. In cases where it is understood that there are reasons for dismissal stipulated in the Turkish Criminal Code or that the condition of investigation or prosecution will not be fulfilled, the case is dismissed. However, in case that the investigation or prosecution is conditional and it is understood that the condition has not been fulfilled yet, a decision to stop is made, pending its realization. This decision can be appealed.

9. In cases where a decision of acquittal can be given immediately, it cannot be decided that there is no room for stopping, falling or imposing a penalty.

10. The decision of non-jurisdiction against a judicial authority other than the judicial authority shall be deemed a judgment in terms of legal remedy.

SECOND PART

Security Measures

Security measures specific to mental patients

Article 57 - (1) A security measure shall be imposed on a person who was mentally ill at the time of the act, for the purpose of protection and treatment. Mentally ill people, who are subject to security measures, are taken under protection and treatment in high-security health institutions.

2) A mentally ill person, for whom a security measure has been ordered, may be released by a court or judge's decision after the report prepared by the health board of the institution where he/she is placed indicates that his/her danger to society has disappeared or has decreased significantly.

3) In the report of the health board, whether medical control and follow-up of the person is required in terms of security, depending on the nature of the mental illness and the act committed, and if necessary, the duration and intervals thereof.

4) Medical control and follow-up shall be provided by the Public Prosecutor's Office by sending these persons to the health institution with technical equipment and authorized specialist, within the period and intervals indicated in the report.

5) In medical control and follow-up, a security measure is taken for re-protection and treatment, based on the report prepared when it is understood that the person's mental illness has increased dangerousness for the society. In this case, the operations specified in the first and the following paragraphs are repeated.

6) on the report of the board prepared in the high security health institution where he/she is placed in accordance with the provisions of the first and second paragraphs about the person whose ability to direct his/her behavior due to his illness has decreased in relation to the act he has committed, the prison sentence to which he/she was sentenced may also be applied as a security measure specific to mental patients, in whole or in part, by a court decision, provided that the duration remains the same.

7) It is decided that people who are addicted to alcohol or drugs or stimulants who commit crimes should be treated in a health institution specific to alcohol or drug or stimulant addicts as a safety precaution. The treatment of these people continues until they get rid of alcohol or drug or stimulant addiction. These persons may be released with a court decision or a judge's decision, upon a report to be prepared in this direction by the health board of the institution where they are placed.

Appointment of the defense counsel

Article 150 - (Amended: 6/12/2006 - Article 5560/21)

1) The suspect or accused is asked to choose a lawyer for himself/ herself. If the suspect or accused declares that he/she is not in a position to choose a lawyer, a lawyer is appointed upon his/her request.

2) If the suspect or accused child who does not have a lawyer is so disabled or deaf and dumb that he cannot defend himself/herself, a lawyer is appointed without seeking his/her request.

3) The provision of the second paragraph shall be applied in investigations and prosecutions made for crimes whose lower limit is more than five years' imprisonment.

4) Other matters related to compulsory defense shall be regulated by a regulation to be issued by taking the opinion of the Union of Turkish Bar Associations.

Alzheimer's Information Book for Patients' Relatives

Dementia and Alzheimer's, the most common type, is a disease that hinders the individual in every aspect. Alzheimer's affects both the patient and their relatives emotionally, socially, economically and physically from the moment it occurs.

This book was written with the aim of helping patients' relatives overcome the problems that often lead them to despair, establishing positive relationships with the patient and reducing the negative effects of the disease. The book is an output of the project numbered 2019-1-TR01-KA204-074782 "Click If You Forgotten / REMEM" supported by the Turkish National Agency within the scope of Erasmus+ Key Action 2 Strategic Partnership. The book was written by the partners of Turkey, Italy and Romania by compiling the information obtained from various sources. We hope that the book will be a light in finding solutions to the difficulties experienced by relatives of Alzheimer's patients.

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