

Eating and Living With Dignity

Practical Guide for Caregivers and
Family Members of Persons With Dementia



Information and Recommendations

The National Program for Addressing Alzheimer's
Disease and Other Types of Dementia



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Information and Recommendations

This booklet was written by professionals at the **Ministry of Health**, through multidisciplinary cooperation. Dietitians, occupational therapists and a speech and language therapist participated in the writing, with the assistance of a social worker and a nurse, in order to collect and complete the information.

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Eating and Living With Dignity – Practical Guide for Caregivers and Family Members of Persons With Dementia – Information and Recommendations

Introduction

Food and eating play an important role in maintaining quality of life, providing pleasure, as well as their important role in maintaining health. Eating is very significant throughout a person's lifetime, even when it seems to us that the person is not functioning at all; eating is one of the last functions that are preserved.

People with dementia experience difficulties in nutrition and eating, which pose a substantial challenge for caregivers. These difficulties appear even in the early stages of the disease, but become worse as it progresses. More often than not, coping with eating difficulties causes great frustration for the primary caregivers and requires reorganization around meals throughout the day.

In view of this, the need arose to provide an answer and solutions for family and caregivers to deal in a dignified manner with the eating difficulties that characterize the various stages of **dementia**.

These information sheets focus on the eating and nutrition difficulties of persons with dementia, and their purpose is to provide practical guidance and assistance **for all caregivers who are dealing with them**, including family, caregivers in the framework of the Nursing Law, foreign caregivers, instructors of support groups for families, employees at long term care facilities and so on – **with the objective of providing adequate nutrition and maintaining the person's safety – while maintaining his dignity at the same time**.

The information presented in these pages is based on vast experience accumulated in Israel and around the world regarding this important issue.

At the same time, it is important that you, the caregivers, take care of yourselves and your health. Sometimes you are so preoccupied and concerned about the patient/your relative, but forget to take care of yourselves: do not pay attention to diet, physical exercise and sometimes even miss family and social events. Without noticing, you might neglect your physical and psychological needs over time, but it is important that you be aware that this is a long-term condition that drains you out and might jeopardize your health, to the point where you can no longer take care of your loved ones. **Therefore it is essential that you take care of your health first and foremost.**

Remember that healthy nutrition and integrating physical exercise into your daily routine promotes your health, for your sake and for the sake of those around you.

For more information please read the chapter at the end of the booklet: "Principles of Healthy Nutrition"

Office of the Minister of Health



Dear citizens,

Life expectancy in Israel is constantly on the rise, which is a great blessing, but one which is accompanied by an increasing number of people with dementia who live to an old age. Dementia patients pose a challenge for the patients' families, society and the healthcare system. Nevertheless, both in Israel and around the world, there is a growing tendency for dementia patients to be cared for by their families at home in the framework of the community. Home care maintains a person's dignity at times when the body and mind are feeble.

Within the framework of coping with dementia, we seek to pay attention to the unique aspects of nutrition and eating patterns of this population, including swallowing difficulties, and how to prevent or minimize consequent health problems.

Generally speaking, education for good and healthy nutrition promotes health and can prevent illness in the general population. And this is also our starting point – food has an important place in our lives. Maimonides, as well as many additional important thinkers in Jewish history, have written much about food products and eating habits in their philosophical, health, and medical aspects; in all his medical writings, Maimonides repeatedly emphasizes the importance of good eating habits as a necessary condition for maintaining a healthy body: “One should refrain from things that make the body ill, and make a habit of things that make one healthy and fit”.

This booklet was written by the multidisciplinary staff at the Ministry of Health in the framework of the National Program for Addressing Alzheimer's Disease and Other Types of Dementia, spearheaded by the Division of Geriatrics at the Ministry of Health.

It contains vital information for all those who take care of people with dementia and for their families. I hope that this information will encourage them and will alleviate the patients' suffering.

Wishing you good health,

Knesset Member Rabbi Yakov Litzman
Minister of Health

Introduction – Head of the Division of Geriatrics



Dementia is one of the most serious and distressing health problems. Dementia is caused by a number of degenerative diseases affecting the brain, the most common of which is Alzheimer's disease. These diseases cause the ongoing and irreversible deterioration of mental capabilities and brain function, posing a challenge for the patient and his family. The first symptoms of the disease are memory loss and impairment in cognitive abilities and orientation, and the person gradually develops an inability to perform daily activities and communicate with his surroundings. Difficulty with nutrition and feeding characterizes the advanced stage of the disease. The purpose of this booklet is to be of assistance and guidance for family members on this subject.

Nutrition is a fundamental and vital part of life for every human being, but for those with dementia, this simple action becomes complex, complicated and sometimes extremely difficult to perform due to the disease's effects – both in terms of health and in terms of behavior. For family members and other caregivers, this vital action of feeding their loved one sometimes becomes an almost impossible mission, and they seek help in coping with the multitude of problems they face on a daily basis.

The purpose of this guidance booklet, written by prominent professionals in the Ministry of Health, including dietitians, occupational therapists, and a speech and language therapist, is to provide families with tools and methods of coping with advanced stage dementia – both in terms of the composition and texture of the food itself, and in terms of methods for feeding, when faced with the challenges it poses for these patients.

I thank the professionals at the Ministry of Health from the Department of Nutrition at Public Health Services, the National Occupational Therapy Service, the personnel of the Division of Geriatrics – from the fields of speech and language therapy, occupational therapy, medicine and nursing – and the Social Work Service, who were part of this initiative, and who worked hard to write, edit and present this information to the families of dementia patients and to other caregivers.

My thanks and appreciation to the EMDA Association – for patients with dementia, Alzheimer's and similar diseases in Israel – which initiates and promotes projects for helping the families of patients with dementia illnesses, and has done so for this important issue of nutrition and feeding as well.

My thanks to ESHEL – the association for planning and developing services for the elderly in Israel – which helped with the process.

The booklet is part of the work done in the framework of the **National Program for Addressing Alzheimer's Disease and Other Types of Dementia**, led by the Ministry of Health, in cooperation with the Ministry of Social Affairs, the Ministry for Social Equality, the National Insurance Institute, the Health Funds and many other bodies.

I wish to express my deepest appreciation for families and other caregivers, who nurse the persons with dementia devotedly. I am certain that this booklet will contribute to more adequate care in terms of nutrition and will assist them in their day to day coping with these patients.

Sincerely,

A handwritten signature in black ink, appearing to read 'A. Cohen', is positioned above a horizontal line.

Dr. Aaron Cohen
Head of the Division of Geriatrics
Ministry of Health

Introduction – EMDA – the Alzheimer's Association of Israel

As life expectancy and the number of elderly people rise globally and in Israel, so does the number of persons with Alzheimer's disease.

Alzheimer's disease has been defined as an epidemic and one of the most substantial public health problems of the 21st century.

This booklet is supplementary to the guidance/recommendations for professionals and the general public, similar to the Complete guide for persons with dementia, Alzheimer's and similar types of diseases, published by the EMDA Association.

Guidelines on nutrition carry a preventative value for all ages, and in particular for the person with dementia.

At certain stages of the disease, nutrition constitutes an important and critical factor in the daily routine for professionals and family members (primary caregivers), when facing the patient experiencing difficulty eating and swallowing.

We are confident that this guide will serve as an important tool for ways to cope with the disease, and will ease, at least a little, the many difficulties that the patient's families and caregivers are facing.

I would like to thank all the members of the committee at the Ministry of Health and the steering committee members for their devotion and dedication to the matter.

Remember – you are not alone – EMDA – the Alzheimer's Association of Israel – *8889, 035341274

A handwritten signature in black ink, appearing to be 'Yona Eliad'.

Yona Eliad
Chairperson

A handwritten signature in black ink, appearing to be 'Gery Rot'.

Gery Rot
CEO

Introduction – Eshel – JDC

(The association for planning and developing services for the elderly in Israel)

In recent years, there has been greater awareness to the fact that healthy nutrition is an essential component of health maintenance and in the prevention of disease, and even contributes to quality of life. Proper nutrition affects health at any age, and more so at times of sickness or at an old age.

Reduced cognitive function affects judgement regarding food intake, could impair the ability to purchase food products and cook them, and could even trigger reactions such as refusal to eat. These difficulties appear even in the early stages of dementia, and become worse as it progresses. In the disease's later stages, there is also difficulty eating and swallowing the food.

Difficulties in nutrition and eating are a challenge for professionals, caregivers and family. These difficulties need to be dealt with on a daily basis, being more often than not a source of frustration for the caregiver (employed) and/or family member.

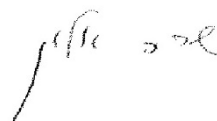
The information sheets focus on these difficulties and focus on practical solutions for all those caring for dementia patients, throughout the stages of the disease.

Prominent professionals from the Ministry of Health, dietitians, occupational therapists and speech and language therapists have joined forces to compose the information sheets. In this booklet, you will find information on the signs of eating and swallowing disorders and difficulties, practical advice and “tips”, including sample menus. The information is based on vast experience accumulated in Israel and around the world regarding this important issue.

Writing and publishing these information sheets is another important step in the efforts made by JDC Israel-Eshel – in collaboration with the Ministry of Health and the EMDA Association – to increase knowledge on the various aspects of dementia at its different stages, and to develop practical and effective tools that will serve all caregivers and make the lives of dementia patients easier. This is part of The National Program for Addressing Alzheimer's Disease and Other Types of Dementia, in which JDC-Eshel participates.

The right professional attitude will help find effective and beneficial solutions for feeding dementia patients, that will maintain the quality of life of persons with dementia and their caregivers.

Sincerely,



Yossi Heiman Dr. Sara Alon

CEO Eshel-JDC Senior program director, Eshel-JDC

Introduction



Department of Nutrition – Public Health Services Occupational Therapy Service and Speech and Language Therapy Service – Medical Administration

Eating is a vital need and a very significant activity in the life of every person. Eating, with everything that goes with it – shopping, cooking, preparing and eating the food – also carries with it cultural, social and emotional significance.

Eating is a complex activity, which depends on physical and cognitive functions, sensory functions, and chewing and swallowing functions. Persons with dementia experience a decline in these functions, which could cause significant impairment of their enjoyment from eating and from the food and also an impairment of safety when eating, and at the same time, prevent participation in important activities that go along with eating, which in turn can cause social isolation.

A balanced and healthy diet is essential at all ages and at all times, and constitutes an important component of health maintenance and quality of life. Lack of a balanced and healthy diet, due to difficulties in eating and swallowing functions, could cause morbidity, such as pressure ulcers, pneumonia and other infections, health deterioration which requires hospitalization – and may sometimes even be life-threatening.

It is therefore particularly important to follow a balanced diet and rules for safe eating with support and guidance from the family and caregivers.

For the dementia patient, quality of life so far as eating and nutrition is concerned often depends on attending staff, family members and primary caregivers. For as long as possible, it is very important to adhere to the wishes and abilities of the person to choose what he wants and prefers to eat, and to maintain a certain degree of independence, even if their environment needs to be adapted for that purpose.

This guidance booklet is a product of the joint efforts by dietitians, speech and language therapists and occupational therapists, who worked together for an important cause – contributing to the quality of life of persons with dementia, and preventing their social isolation, as far as possible, while addressing many issues and in taking into consideration their health and functional state.

We wish to express our thanks and appreciation for all those participating in the project: people in the Ministry of Health and other partners who worked hard to realize this important guidance project for the benefit of the patients and their families.

Sincerely,

Prof. Ronit Endevelt – Director, Department of Nutrition

Orly Boni – Director, National Occupational Therapy Service

Dr. Orly Herzberg – National Speech and Language Therapist

Ministry of Health



Eating and food intake in the healthy person – what does it involve?

Eating is a much more complex action than simply putting food in the mouth. It consists of several stages:

- a. Buying the food
- b. Preparing the meal
- c. Organizing the eating environment – such as setting the table
- d. Eating the food

a. Buying and storing the food

This stage begins before the meal itself, when we walk or drive to the market or store, remember what we wanted to buy, choose what we want to buy, the quantity we need (such as 1 kg of tomatoes and a loaf of bread), pay, go back home and organize the food in the cabinets and fridge.

b. Preparing the meal

We plan what we want to eat, whether it be a simple meal that doesn't require special preparation (slice of bread with cheese) or a more complex meal that requires preparation (such as chopping salad or cooking soup, baking a pie or frying meatballs). We can cook by a recipe or from memory.

c. Organizing the eating environment (e.g. setting the table)

In a healthy routine, we are able to choose and plan when to eat our lunch, where to eat our lunch (kitchen? dining room?) and who we want to share our meal with (alone? with friends? with the kids?)

We set the table – spread a tablecloth, select a plate, a glass, utensils (knife, fork, spoon) with which we'd like to eat.

Usually we can also choose whether we want to eat in a room lit with a strong or weak lighting, whether we want to eat with background music or quietly – and all this even before we began eating (ambiance).

d. Eating the food

While we eat, we can feed ourselves, we choose the eating pace (slowly and relaxed or fast), and we are able to chew and swallow well different types of food and beverages. We are able to use our senses – see, smell and taste the food. Accordingly, we can decide – whether we would like another piece of pie, more vegetable salad or decide that we don't want to finish the food on the plate. We are then able to clear the dishes to the sink and wash the dishes.

Not all of us do all of the actions described above. For example, common practice in many families is that only one spouse does the shopping, while another usually cooks or washes the dishes.

This division of labor is made out of choice and not due to a real difficulty in performing one of the actions.

The difficulties described below relate to those experiencing difficulties in performing actions they were used to doing beforehand.





Why do persons with dementia have difficulty eating?

Dementia itself can affect eating: Dementia is characterized by cognitive changes that progress with time and that affect comprehension, memory and orientation – each of which has many effects on eating and nutrition functions.

In the first stages of the disease, when the person with dementia feels that “something is wrong with him”, there may be reactions of depression, anxiety and disquiet (which may be manifested in wandering around the house day and night or difficulty sitting in one place and concentrating). These effects influence eating and food intake. For example, when wandering a lot, the body expends much energy (calories) and this causes weight loss, even more exacerbated when nutrition is inadequate.

Significant events in the patient’s life could cause emotional difficulty and loss of appetite: For example, illness or death of spouse or other family members or friends, change in living environment (such as moving close to the children or to sheltered housing). In addition, social isolation and absence of purposeful occupation affect nutrition.

Xerostomia (dry mouth): There may be several causes for this: reduced amount of saliva (due to insufficient fluid intake, medications and so on) combined with changes in saliva composition, making saliva more viscous. Additionally, elderly persons tend to breath through the mouth, leaving their mouths open all the time, and the oral cavity becomes dry.

Oral cavity problems: Includes dental problems, problems in palette, gums and tongue. All of these can affect the choice of type of food (for example, preferring meatballs over schnitzel, mashed potatoes over baked potatoes), refraining from eating foods that are too spicy or sour.

Teeth have a crucial influence on the eating process. Bad and untreated teeth are painful and can cause difficulty chewing, and dentures that fit poorly on the gums can cause infections and pain. Infections in the oral cavity, such as oral thrush (recognizable as a white coating on the tongue and/or sores), inflamed gums, jaw pain and so forth – also make eating difficult.

Pain: Pain of any type which is bothersome and troubling and can affect food intake.

Sickness: Including inflammations and infections (such as urinary tract infection and pneumonia) – could cause general weakness and affect appetite and the ability to swallow.

Medications: Many adults, in particular elderly persons, suffer from multiple illnesses and are therefore treated with a wide range of medications. Some medications affect various functions: alertness, thinking, hunger and appetite, swallowing process, and some medications cause nausea or constipation. As a result, appetite and the desire to eat is affected.

Constipation – many people, in particular the elderly, complain of constipation, which might be accompanied by abdominal pain, fullness and flatulence and strain on the toilet (which could cause hemorrhoids and bleeding). This range of effects causes loss of appetite. Persons with dementia are sometimes unable to express their sensations in words and complain that they are constipated, but we can see that they are suffering from this by their expressions and body language.

There are many reasons for eating difficulties in persons with dementia. In many instances, they can be helped. We recommend consulting the patient’s physician.

Weight changes:

Eating problems in persons with dementia, at the different stages of the disease, could cause weight loss or even significant weight gain. Therefore, it is important to be weighed once a month.

If there is a weight loss of more than 5 kg over a period of 6 months, contact the patient’s physician and consult a dietitian.



What are the signs that can indicate problems with eating and with choosing food?




Warning signs

Even in the early stages of dementia, difficulties can be identified in each of the four eating function actions – buying food, preparing the meal, organizing the place where we eat, and eating the food (as aforesaid).

These difficulties are warning signs, indicating that the person with dementia is not functioning as he has up till now, and he needs help.

Here are the warning signs for each of the four activities required for eating function.

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- The tips and recommendations presented here are particularly important in the early stages of dementia.
 - The nature of the disease and the rate of its progress vary from one person to another, so there is no single solution that fits everyone and for all circumstances.

Note: These tips can also help the healthy population and people suffering from various disease not related to dementia.

a. Buying and storing food

- ❗ Does grocery shopping take too long?
- ❗ Does the person shop for groceries in a disorganized and inefficient manner? For example, does he buy fruits and vegetables, then buy dairy products and then go back to buy more vegetables?
- ❗ Does the person have trouble handling money? For example, does the person with dementia fill a whole cart with groceries even though he has only ten Shekels in his wallet?
- ❗ Does the person have difficulty choosing the groceries? For example, buying ten packets of margarine while forgetting to get what he really needs: milk, eggs, vegetables, bread.
- ❗ Does the person go shopping for groceries often, but there is only a small amount of food in the house?
- ❗ Has there been a change in the choice of foods that the person buys and eats? For example, does a person who always ate the same kind of bread and made sure to buy only 5% fat soft cheese suddenly start buying different kinds of breads and high-fat cheeses?
- ❗ Is there more food than necessary in the fridge?
- ❗ Is there food in the fridge that has gone bad?
- ❗ Is the food that was bought stored in the appropriate place? Or do we suddenly find ice-cream or frozen meat in the kitchen cabinet and fresh cucumbers in the freezer?

b. Preparing the meal

- ❗ Does the person forget how to cook familiar dishes?
- ❗ Does the person behave dangerously in the kitchen? Examples: Forgetting a pot on the gas, or leaving a baking dish in a lit oven, or heating oil in the frying pan and forgetting it until there is the smell of burnt oil, or pouring hot water from the kettle and getting burnt.
- ❗ Does the person keep cooking rice over and over again, even when there is enough cooked rice?
- ❗ Has the person stopped preparing cooked food?

c. Organizing the eating environment (such as setting the table)

- ❗ Are meal times not organized, or does the person suddenly eat breakfast at noon and dinner at two o'clock at night? Has there been an extreme change without a justified reason?
- ❗ Does the person forget to eat or does he eat incessantly?
- ❗ Has there been a change in eating habits or eating place – has the person suddenly begun to eat in a place where he did not usually eat in the past, e.g. in the living room? In the bedroom? On the porch?
- ❗ Does the person have trouble getting organized to host meals, especially trouble setting the table?
- ❗ After the meal – is the table cleared as in the past? Are the dishes being washed? Is the leftover food being stored? Are the dishes returned to their usual place?

d. Eating the food

- ❗ Has there been a change in table manners at meal time? Does the person no longer care when his clothes get dirty during a meal?
- ❗ Has there been a change in the duration of the meal, e.g. eating very rapidly or the meal takes a long time? Does the person not finish the meal?
- ❗ Does the person eat very little?
- ❗ Does the person eat a large meal and then say “I haven’t eaten a thing” or “I haven’t eaten”?
- ❗ Does the person refuse to open his mouth? Does the person leave his mouth open all the time?
- ❗ Does the person complain that food “gets stuck” in his throat? “I can’t swallow”?
- ❗ Does the person leave the food in his mouth for a long time without swallowing? Chew for a long time? Swallow fast without chewing?
- ❗ Does the person cough while eating/drinking or immediately afterwards?

These warning signs could indicate a medical problem that requires investigation and diagnosis – see the patient’s physician at the Health Fund (kupat cholim).

Delayed diagnosis and treatment could make things worse.



Tips and recommendations for coping with eating function problems in persons with dementia

The Problem	Recommendations
a. Buying food	
Unable to go grocery shopping because he has stopped driving	Find an appropriate time to drive him to grocery shopping or encourage him to use public transportation.
Has trouble shopping for groceries because of weakness and difficulty bringing the food home	Encourage him to use a shopping cart or to use a delivery service or to shop on the Internet, with supervision and support.
Does not remember: “What did I want to buy?”	Leave a notepad with a pen or pencil at a fixed spot in the kitchen and prepare a grocery list. Take the grocery list when going shopping.
Difficulty managing money	A family member should set a fixed amount in advance, make sure that the person with dementia goes shopping with the grocery list, or accompany him on his shopping and pay for him.
Buys excessive amounts of food, some of the food is not healthy	Accompany him on his grocery shopping as often as possible.
We wish to check if there is food that has gone bad and/or not healthy in the fridge or cabinet without hurting his feelings	It is important to find an excuse to open the fridge or cabinet without hurting the person’s feelings. Say out loud: “I’m going to get a glass of milk from the fridge”.
We found food that has gone bad in the fridge many times and the utensils are very dirty, which poses a health hazard	Urgently consider the provision of assistance on a more intensive basis.
b. Preparing the meal	
The person forgets how to cook familiar dishes	Prepare familiar recipes together, check together the recipe’s ingredients and method of preparation, try to break down the recipe into stages and select the stage that carries most importance for the person. For example, when preparing cookies – prepare dough in advance and have the person with dementia only make the shapes.
The person forgets pots on the gas, baking trays in the oven, oil in the frying pan	Use an alarm clock to remind him when to turn off the oven or the gas. Use a leak proof gas stove – check with the manufacturer. Another option – installing such a mechanism. You can purchase such a mechanism at “Yad Sarah”. Consider using an electric stove – this prevents the risk of a gas leak but does not prevent burns.

The Problem	Recommendations
The person is not careful when preparing hot beverages	Make sure he can use an electric kettle/hot water urn/thermos flask and remembers how to use it. Make sure that the person can use these without getting a burn.
Repeatedly cooks the same dish, even though the same dish, recently prepared, is in the fridge or on the counter	Requires attention. In this case, it is recommended to make sure that there are not excessive amounts of raw ingredients at home, such as bags of rice, flour or pasta.
Difficulty finding pots and cooking utensils	Organize the kitchen so that the commonly used dishes and cooking utensils are stored in an easily accessible place. Remove items that are not in use.
Difficulty climbing or bending down in order to find cooking utensils	Organize the kitchen so that the utensils necessary for everyday use are at hand without having to climb or bend down. Under all circumstances, refrain from climbing a ladder or standing on a chair without supervision, to prevent falls! If dishes that are not in everyday use are needed, when hosting for example, family members should get the dishes down from high storage and bring them to the table.
Difficulty planning and preparing a holiday meal	Prepare as early as possible and avoid cooking at the last minute. We also suggest making it easier and preparing a cake or favorite family dish together, thus maintaining the person's dignity.
The person has stopped preparing cooked food	Provide ready cooked food on a regular basis.

c. Organizing the eating environment

Disorganized meal times	Organize ready made meals with a note "breakfast", "lunch", and call to remind the person to go to the fridge and get the proper meal. If the person still can, prepare a tracking table marked "I ate breakfast".
Change in the eating place	It is important to make sure that the eating place is suitable for safe eating, that the way from the kitchen to the eating place is clear of physical obstacles, and that the change in the environment does not affect the food being eaten. For example: if instead of healthy meals in the kitchen, the person starts eating only in front of the TV, it is important to make sure that there are no obstacles on the way to the living room, that the couch is placed opposite a table and at the right height, and that the person doesn't eat only snacks and sweets due to the environment.
Environmental factors that interfere with eating	Pay attention to lighting, sitting comfort, the distance between the chair and the table. It is very important to eat in a quiet and calm setting with few distractions, especially in the presence of agitation and/or suspected swallowing problems.

The Problem	Recommendations
Difficulty setting the table	<p>If the person finds it difficult to set the table as customary when hosting, we recommend doing it together with the person, or doing it instead of him, to allow him to host.</p> <p>If the person is unable to set the eating environment for a simple everyday meal – help is necessary!</p>
Difficulty clearing the dishes and washing them after a meal	Help is necessary.
<p>d. The actual act of eating</p> <p>General: It is important to come for visits at mealtimes. Such visits can help maintain a schedule and help the person eat a diversified and organized meal.</p>	
Difficulty using utensils	<p>Sometimes, an adapted eating utensil – such as a plate fixed to the table, a caring mug, personally adapted utensils¹ – can facilitate eating functions and make it more convenient and safe to eat. We recommend consulting with occupational therapists.</p> <p>For details on eating aids, refer to the end of the booklet.</p>
Overeating	<p>Organize the food in the fridge in sealed boxes to prevent temptation to overeat.</p> <p>It is very important that the food is not visible and available: don't leave a jar of cookies or candy in a visible and tempting place. You can leave a bowl with sliced vegetables or some fruit for snacking.</p> <p>You can allow the person to eat small frequent meals to satisfy the need to eat.</p> <p>We recommend organizing an interesting occupation indoors and outdoors to prevent unnecessary eating due to boredom.</p> <p>If the problem is not serious and there is a little weight gain – there is no room for concern. Sometimes it is even better that the person is a little overweight (reserves). On the other hand, if the “binging” problem gets worse and you lose control over matters, you should try consulting a dietitian.</p>
Strong need and desire to eat sweets – chocolate, cakes, candy...	<p>Try giving small portions of sweets at a time so that the person does not eat excessively: one piece of chocolate, one biscuit...</p> <p>Offer other foods as well, sweet but healthier – such as a piece of fruit or fruit salad, fruit yoghurt, chocolate milk, dried fruit (if teeth condition allows)...</p>
Change in table manners: the person no longer cares if his clothes get dirty	Help is necessary. Hand out napkins over the course of the meal, wash his face, change clothes after the meal.

The Problem	Recommendations
Eats very little	<p>Try to find out the reason: misfit teeth, depression/anxiety, acute disease... In these cases, see the family physician.</p> <p>Divide to small meals throughout the day.</p> <p>It is better to drink only after the meal and not before, so that the person does not fill on water.</p> <p>It is important to make sure that the food is appetizing – served nicely, contrasting tastes, tempting colors and smells. When the person smells the food ready and being cooked – it makes him want to eat.</p> <p>If the person wants to feed himself but is unable to hold utensils (spoon, knife and fork), you can serve food that he can eat with his hands (“finger food” – see details below).</p> <p>When the food is not tasty, try finding out the reason – maybe the food is not hot enough or cold enough, maybe it is missing sugar, spicy seasoning or another favorite flavor.</p> <p>Experience shows that breakfast is taken better than dinner. However, if the person with dementia is awake and more active at nighttime, offer him food at those hours as well.</p>
Drinks little or refuses to drink	<p>For those who are alone for part of the day without help or supervision, we recommend creating a routine of drinking from water bottles. You can label each bottle according to the days of the week and instruct the person with dementia to drink at least the entire bottle of that day. This is like the pill box that helps getting organized with taking medications at fixed times.</p> <p>If our loved one refuses to drink, you can try telling him that “the doctor said you have to drink”!</p> <p>You can make drinking into a ritual or pleasant experience that makes the person feel good, for instance: “Mom, I made us a nice cup of coffee/tea the way you like it. It’s nice to drink together”.</p>
Holds the food in the mouth; Chews for a long time; Coughs while eating/drinking or immediately afterwards	<p>- Consultation may be necessary, focusing on the adaptation of food textures and ways of eating and feeding.</p> <p>Persons with dementia need a longer meal time. It is recommended to dedicate at least one hour for every meal.</p> <p>It is recommended to divide the meals into a larger number of smaller meals throughout the day.</p> <p>It is important to check that the mouth is empty at the end of the meal.</p> <p>Wait about 30-45 minutes after the meal before lying down.</p> <p>See a physician, speech and language therapist and dietitian for assessment and counselling.</p>

It is important to monitor, obtain advice and adapt the solutions to the changing situation:

- If a person has dementia, it is very important that his family or caregivers visit him as often as possible and be aware of the changes that occur. These regular visits are vital and allow to observe the person's functioning and behavior.
- These visits are also important in order to identify danger, for example: a person who forgets a pot on the stove, eats bad food from the fridge or a person who forgets to eat and drink – puts his health and the health of those around him at risk to the point of mortal danger!
- When the family lives far from the relative with dementia: contact a neighbor or friend who lives close by, and ask him to visit and observe the situation. It is important to alert the visitor's attention to the situations mentioned above.

If there is danger – constant help and escort is needed for the various activities.

Consult a physician, nurse and social worker.



Eating with fingers – “finger food”

Often enough, persons with dementia find it difficult to eat independently with a knife and fork. There can be many reasons for this: sometimes the person with dementia is unable to understand the function of the knife and fork, and sometimes he experiences motor difficulties, such as hand tremors or he is unable to hold a knife. In these cases, it is important to allow the person to try eating “finger food”.

- Finger food is food that you can eat with your hands.
- When this food is served to a person with dementia, we help him feel that he is independent, and can eat by himself and feel that he is still in control of his eating.
- Finger food can be an entire meal or part of a meal, for example: a slice of bread, a piece of fruit or vegetable or French fries.
- You can give finger food at all meals and also in between meals.
- It is important to adapt the food to the person’s preferences and to his ability to chew (or offer soft foods when these are needed).



Example of a daily menu of 5 meals a day as recommended, composed entirely of finger food (except for the beverages).

Breakfast:

- Hard or filled egg (for example with avocado, tahini, mayonnaise) or slices of omelet.
- Sandwich cut into small pieces with avocado, tahini, hummus, peanut butter, mayonnaise, butter, soft cream cheese, melted cheese, hard cheese, sardines or tuna in oil, omelet, egg salad, halva, matbucha (cooked tomato salad) or Turkish salad and any appetizing food that makes the person want to eat.
- Fresh, sliced vegetables, such as: tomato, cucumber, pepper of different colors, radish, kohlrabi, carrot.
- Beverage.

Mid-morning snack:

- Sliced seasonal fruits in different colors, for example: apple, watermelon, cantaloupe, peach, orange, banana, strawberry.

Lunch:

- Cooked or baked potato, in slices that are convenient to hold with the fingers.
- Wide noodles/pasta that it is easy to pick up with the hands, in thick sauce.
- Cooked favorite vegetables – pieces of zucchini, carrot, cauliflower, pumpkin, sweet potato, green and yellow beans, fava beans, peas...
- Fried or baked fish fingers; slices of chicken; cut schnitzel; all types of minces – such as: leek; beef, chicken, turkey or fish balls or cutlets; stuffed kubbeh; small chicken drumstick; pancakes made of pulses...
- Beverage.

Afternoon snack:

- Cut sandwich or fruit or piece of cake or cookie that is easy to hold.

Dinner:

- The same as in the morning, or make variations and add foods such as:
- Cubes of hard cheese or melted cheese.
- Pies cut into small pieces or baked in a muffin pan.
- Pizza squares, cut pancake or crepes (blinches), stuffed vine leaves.
- Whole sardines or mackerels, strain the oil.
- Beverage.



How to handle constipation

As noted previously, many people, in particular the elderly, complain of constipation, which might be accompanied by abdominal pain, fullness and flatulence and the need to strain on the toilet (which could cause hemorrhoids and bleeding) – all these effects and sensations cause loss of appetite. Persons with dementia are sometimes unable to express in words their complaint that they are constipated, but sometimes we can see that they are constipated by their facial and body expressions.

Why does this happen and what to do?

- The digestive system slows down as we age; use of certain medications can aggravate the situation.
- Due to eating too little, and in particular a diet that is not rich in fiber (**see below regarding how to increase fiber intake in food**).
- When the person doesn't drink enough – the stool becomes hard – **see below explanation on the importance of drinking**.
- Inactivity and extended periods of sitting make the bowels “lazy” – the person should be encouraged as much as possible to engage in physical activity suitable for him, after consulting the physician and physiotherapist.
- The person sometimes forgets to go to the toilet and then the stool becomes harder. Therefore, it is very important that the person gets used to going to the toilet regularly, for example: if he is used to go to the toilet after breakfast, keep this habit.
- **If all attempts to treat the problem using the methods specified above are unsuccessful, consult the physician.**





Natural dietary fiber prevents constipation!

Many foods contain fiber, which helps digestion and to balance blood sugar and lipid levels. Making sure to drink sufficient fluids, as well as eating high-fiber foods, is important in order to prevent constipation. It is highly recommended to include these foods in the daily diet. These foods are in the grains group and in the fruit and vegetables group as well as in pulses.

- **Whole grains:** whole wheat and whole wheat breads, oatmeal, whole rice, whole wheat noodles and pasta, buckwheat, groats (bulgur), cracked wheat, whole semolina, corn.
- **Pulses:** beans of all colors and kinds, peas, chickpeas, lupine bean, lentils, black-eyed peas, fava bean.
- **Fruit and Vegetables** of all colors and kinds. Wash them well and serve unpeeled, if possible. At meals and between meals, it is recommended to eat fresh fruit and vegetables: you can slice them and serve as an alternative to salty snacks – slices of cucumber, carrot and celery sticks, slices of seasonal fruit etc.

Drinking – important and also helps prevent constipation

Many people don't feel the need to drink or sometimes forget to drink. Insufficient fluids can cause confusion, fatigue, headaches, constipation and urinary tract infections. Drink copious amounts of water throughout the day, at meal times and between meals. Below are several tips for encouraging the person to drink:

- **What is the recommended amount of water to drink?** It depends on the weather, the amount of salt we eat, body weight, physical exercise. In hot weather – we sweat a lot and need to drink more; you can also tell by the color of the urine: if it's light colored, this indicates that we drank enough. If it's yellow or dark, we need to drink more.
- **When to drink** Serve beverages at meal times and also between meals.
- **What to drink** It is best to serve water at the temperature that the individual prefers: some prefer cold water (mainly in summer) and others prefer water at room temperature. Offer a beverage with a different and interesting flavor each time: you can add flavor to the water with a slice of lemon or mint leaf. It is preferable to use a transparent glass, so you can see its contents. Explain what's in the glass and at which temperature: "Dad, I brought you a glass of cold water/ hot tea with sugar/ fresh orange juice."
 - Tip: At advanced stages of the disease, sweetened beverages are also an option, to encourage the person to drink.
 - **Moderately drink** regular and green tea, coffee, chocolate milk, coke and energy drinks, in amounts that are not excessive, since they contain caffeine. Too much caffeine can result in difficulty falling asleep at night or at noon, disquiet, agitation, tremors, frequent urination, irregular heart rhythm, digestive problems etc.
 - **Alcohol consumption:** Small quantities of alcohol (such as a glass of wine or beer) are usually harmless, but regular consumption of large quantities of alcohol causes confusion, disquiet and agitation and serious physical harm.



Going up a notch – when dementia progresses

The progression of the disease is gradual and individual. The person may still be able to eat independently but need to be served on the plate. Sometimes, verbal encouragement may be sufficient. If this is the case, it is best to simply and kindly remind the person: “eat please”.

As the disease progresses, the time comes when the person is unable to remember the steps of eating and does not even understand the instruction “eat please”. These changes will necessitate changes in the foods themselves, in their composition and in the methods of feeding.

It is important to be alert at mealtimes: If the person coughs during meals or immediately afterwards, this may indicate a swallowing problem (see details below). If this is the case, it is important to see the family physician and bring his attention to the fact that there might be a swallowing problem and suggest a consultation with an ENT (ear, nose and throat) specialist and a speech and language therapist.

Pain, constipation and oral problems: As indicated above – these conditions are very common among the elderly, particularly among dementia patients, and could get worse in the advanced stages of the disease. At the same time, the patient’s ability to express pain or discomfort diminishes due to these conditions, and therefore it is important to initiate monitoring and treatment even without explicit complaints on the patient’s part.

Medications: In the advanced stages of dementia, the use of medications in general increases, particularly the use of medications that affect behavior or pain relief medications – and there are more side effects, which might impair alertness, cause loss of appetite, difficulty swallowing. All of these have a direct influence on eating.

Teeth: The person with dementia could have problems with their teeth just like anyone else, but in the advanced stages of the disease, he will have trouble expressing himself and pointing to the source of the problem. This in turn will cause late diagnosis and delayed treatment, and the problem will worsen to the point of causing pain, difficulty chewing, refusal to eat, weight loss, restlessness, introversion and other behavioral changes. Prevention – it is important to construct a personal treatment plan with the dentist, tailored for the person with dementia. It is important to pay attention to signs such as a broken or loose tooth, misfitting dentures, sores in the oral cavity, and in general – any behavioral change that appears close to meal times or during meal times which could indicate dental problems.

Xerostomia (dry mouth): Xerostomia is common in diseases such as diabetes and as a side effect of some medications, such as medications against high blood pressure, allergy, depression etc. Xerostomia can cause difficulty chewing and swallowing, damage to teeth, thrush and even impaired speech. Make sure to drink plenty of fluids, maintain oral hygiene and consult the patient’s physician.



Changes in eating and swallowing as manifestation of dementia progression

Changes in the cognitive state and changes in state of consciousness in the person with dementia could manifest as drowsiness, reduced communication with his surroundings, the patient's inability to express himself and his wishes, and lack of understanding of the eating situation and of the stages of eating.

Sensory impairment- As the disease progresses, there is diminished reaction to the sense of taste, of smell and to the sounds of the eating utensils, which are typically the initial stimulation before swallowing.

Swallowing problems – swallowing is the process of transferring food through the mouth into the pharynx and from there to the stomach. Swallowing is a complex process, involving an entire system of muscles and nerves.

As the disease progresses, nerves and muscles involved in the eating and swallowing process are affected, and this causes swallowing problems that can affect nutrition, and at the same time can cause food to enter the lungs, resulting in cough and asphyxiation when eating, recurring pneumonia, and can be life threatening.

What are the signs of a swallowing problem?

- ❗ The person reports food getting stuck in his throat
- ❗ Recurring disease of the airways, such as pneumonia
- ❗ Unexplained fever
- ❗ Marked weight loss
- ❗ The person coughs or clears his throat when eating and/or drinking
- ❗ Change in breathing or strained breathing when swallowing
- ❗ The person holds the food in the mouth
- ❗ The person refuses to eat
- ❗ Food remains in the mouth after swallowing

One or more of these signs may indicate a swallowing problem!

See the patient's physician without delay – for investigation and appropriate treatment

Practical advice and tips that are useful before, during and after meals – at the advanced stages of dementia:

As the patient's condition worsens, the need grows for the presence of another person to assist throughout the day and often through the night as well. At this stage, the caregiver is often required to help not only in the preparation of food and in organizing the environment, but also with the act of eating itself.

Before the meal:

- ! Make sure the person with dementia is as alert as possible. We recommend doing anything that from your experience, wakens your loved one, such: talking to him, playing favorite music, gently touching the face and hands...
- ! Notice the posture in which the person is sitting: make sure that the person is in a position which is closest to sitting. It is especially important that the head is upright and not dropped.
- ! Keep a habit of eating in specific places in the house, such as the kitchen, dining room, or garden.
- ! Make meal times pleasant by changing or adapting the eating environment: such as eating next to a table (even if he does not feed himself), turning on a pleasant light or opening the shades/window, quiet relaxed atmosphere or playing appropriate music.
- ! Check whether the person with dementia prefers to eat with or without dentures.
- ! Make sure that if he is used to eyeglasses and a hearing aid, he uses them during meal times as well.
- ! Make sure the mouth is moistened/wet before beginning the meal. You can drop several drops of sugar water.
- ! Saliva production can be stimulated by using an adult teether, like the kind used for babies when they are teething. Biting stimulates saliva production and preserves the mobility of the muscles of the mouth.
- ! Make sure to prepare food of a texture that suits the patient's condition. Use appropriate appliances for preparing the food, such as: food processor, blender, hand blender, grater.
- ! Serves at least six meals a day.
- ! If the person is sometimes more alert at night, use this for a meal.



During the meal

- ❗ Never compel the person to eat or force his mouth open against his will.
- ❗ While eating, talk to the person and explain what you are going to do together. It is important to speak in short sentences: “Now we are going to eat ice-cream”.
- ❗ It is important to maintain eye contact during the meal to encourage interpersonal communication.
- ❗ Pay attention to verbal reactions, facial expressions and body language in reaction to the food. This way we can identify pleasure, comfort, pain, suffering.
- ❗ Speak gently and calmly to alleviate concerns and fears. It is important to understand that the person may not understand that he is now in an eating situation and he may not recognize objects, so he might be frightened when he sees a spoon approaching his mouth.
- ❗ Suitable food textures: change the texture of the food to accommodate the person’s general medical condition and his swallowing ability. For example, if it is hard for him to chew hard and solid food (such as: apple/beef/cucumber), switch to softer food texture (cooked cutlets/cooked vegetables/cooked fish with sauce). If eating and swallowing abilities diminish significantly, switch to a thick and homogenous pureed texture, such as apple puree/food mashed in the blender or dairy dessert.
- ❗ Allow a break between spoonful and the next. Remind the person to swallow.
- ❗ If he coughs during the meal – see the patient’s physician and if necessary, see a speech and language therapist for assessment of swallowing functions.

After the meal

- ❗ It is important to maintain oral hygiene and cleanliness: clean food residue that remains in the mouth and wash dentures (if any). Use a soft brush and a toothpaste that the person likes and is used to.
- ❗ Cleaning of the oral cavity must be done gently and carefully so as not to induce vomiting or cause an injury.
- ❗ Do not let the person lie down immediately after the meal, in order to allow food to digest and to prevent food from entering the windpipe and lungs.

Tips and advice – what to eat in the advanced stages of the disease

- In respect of patients with dementia who have problems with nutrition and eating, it is important **to focus as much as possible on improving the quality of life through nutrition**. This is not the right time to be strict about sugar or salt intake or about weight loss diets. **Allow the person to eat what he loves and enjoys**.
- In general, it is best to serve food that is seasoned with diverse spicy, sweet, sour flavors, depending on the person's personal taste. Seasoned food is appetizing, keeps the person alert and encourages him to swallow.
- When he has mouth sores, avoid excessive seasoning and avoid food that is too spicy or too sour.
- Depending on his condition, you can try and engage the person in the choice of foods from the list of options attached below.
- It is very important to make sure to drink throughout the day.
- At these stages, you may have to switch to drinking using a straw, a bottle or a special cup, or even with a spoon. We recommend consulting with occupational therapists to select the appropriate aid.
- Nevertheless, take note that liquids can sometimes cause coughing, so you can use a thickening agent, which you can buy at the pharmacy, following consultation with a speech and language therapist.
- Food and beverage temperature: make sure that the food you serve is neither too hot nor too cold. Food which is too hot can cause burns; food which is too cold can cause cramps of the muscles of the mouth. In addition, for many people, heat and cold can cause pain due to gum inflammations, cavities and dentures.



Soft and nutritious foods

For people with eating, chewing and swallowing problems

Breakfast or dinner:

- Porridge with added: sugar or honey, sweet or sour cream, jam, chocolate.
- Dairy dessert in various flavors.
- Cooked pudding based on whole milk with cream.
- Spreads: avocado, tahini, hummus, smooth peanut butter, egg salad with mayonnaise, soft cream cheese, tuna salad with oil mashed in the blender.

Lunch:

- Mashed potatoes/sweet potatoes with gravy.
- Thick and smooth soups without vegetable pieces, with added pulses (such as lentils or peas), rice, barley groats, pasta. You can add egg drops to the soup.
- Pureed fish, chicken or turkey with gravy.

Between meals (“mid-morning snack” and “afternoon snack”):

- Apple sauce with added sugar, honey etc. (as for porridge), smooth peanut butter without pieces of peanuts, raw tahini.
- Fruit or ice-cream mashed in the blender with juice, milk or sweet cream (milkshake), mashed to a smooth, homogeneous texture.
- Halva spread (can be prepared by mixing date honey or honey with raw tahini).
- Ice-creams and popsicles.

When you want to enrich the diet, prefer regular food over using preparations or dietary supplements and oral nutritional supplements. When there is no choice, integrate the supplements into the menu – it is important to consult a dietitian.



In the advanced stages of dementia, you may feel it is very hard to take care of your loved one's nutrition.

There may be situations where there is significant weight loss or when you notice that despite that vast amount of time you invest in feeding, the amount of food that your loved one is eating is very small.

It is a good thing to seek the help of professionals under such circumstances. The family physician or the nurse at the clinic will guide you to appropriate consultation so you can find the most appropriate way to help your loved one.





Principles of healthy nutrition

Healthy nutrition combined with physical activity is important at all ages. The food pyramid demonstrates this.

Structure of the food pyramid

You can look at the food pyramid from inside or from outside. Inside the pyramid= Recommendations for nutrition; everything around it= recommendations for physical activity. Physical activity combined with proper nutrition = recipe for good health.



Inside the pyramid:

The pyramid consists of six levels, each containing a different food group: five levels with groups of recommended foods, and a sixth level, containing foods that the body doesn't need.

The quantities of the recommended foods are described in the following manner: you should eat less the higher you are toward the top of the pyramid.

For example: you should eat more from the grain family (such as bread) than from the high-fat foods. Each level of the pyramid consists of food groups:



Food groups

The six food groups of the pyramid:

Water

Tap water is recommended for consumption and it is a waste to spend money on purchasing and transporting bottled water.



Grains and pulses-

For example, bread, noodles, rice, potatoes, corn, barley groats, semolina, oatmeal and so on.

We recommend choosing whole grains, for instance: whole wheat bread, whole rice, unpeeled potatoes, whole wheat, oatmeal and so on. These grains are rich in fiber, vitamins and minerals.



Fruit and vegetables

We recommend eating at least five unpeeled fruits and vegetables of various colors every day, for example, three vegetables and two fruits.



Protein rich foods:

Meat and poultry products, dairy products, eggs, pulses and fish.

It is important that every meal contains at least one serving from this group – for example, dairy products or egg in the morning and in the evening, and at lunchtime, chicken, fish or pulses.



High-fat foods

For example: avocado, tahini, oil, olives, mayonnaise, nuts and peanuts. When preparing food, it is better to use canola oil or olive oil than butter or margarine.



Candy, snacks, sweet drinks –

This group is not recommended, but as aforesaid, it is an occasional source of pleasure for many people.

Note: As noted above, in persons **with advanced dementia**, do not be strict about avoiding this food group.



You are not alone

At any stage and in any situation, you don't have to cope with the problem alone. Seek the help of professionals. The family physician can diagnose problems that arise, and as necessary, refer you to a dietitian, an occupational therapist, a speech and language therapist. You can also consult, as necessary, a nurse or social worker.

Who do I contact?

The Health Funds (kupot cholim)

As noted above, when you experience some difficulty, we recommend that you see a professional at the Health Fund with which the person with dementia is insured.

Below are the telephone numbers and website addresses of the four Health Funds:

Clalit Health Services *2700	http://www.clalit.co.il
Maccabi Healthcare Services *3555	http://www.maccabi4u.co.il
Meuhedet Health Fund *3833	https://www.meuhedet.co.il
Leumit Health Fund *507	http://www.leumit.co.il

Information and support on dementia

Information on dementia and Alzheimer's disease on the Ministry of Health website <http://www.health.gov.il/Subjects/Geriatrics/Dementia/Pages/default.aspx>

EMDA – the Alzheimer's Association of Israel- <http://www.alz-il.net> Tel. *8889 Tel. – 1700-700-204

Melabev Association- www.melabev.org.il Tel. 1-700-70-4533

Eating accessories

You can consult an occupational therapist at the Health Fund regarding the accessories appropriate for the condition of the person with dementia.

You can look at possible accessories on:

Milbat Association – www.milbat.org.il Tel. – 07-22230007

Azarim website- <http://www.azarim.org.il>

Yad Sarah – <http://www.yadsarah.org.il/> see exhibition and counselling centers

General information

Varied information on old age on the Ministry of Health website

<http://www.health.gov.il/Subjects/Geriatrics/Pages/default2.aspx>

Information on rights and services for the elderly on the Ministry of Health website

http://www.health.gov.il/Subjects/Geriatrics/rights_and_services_for_elderly/Pages/default.aspx

Reuth Eshel Association – <http://www.reutheshel.org.il/>

