

Ja želim sa demencijom, ali...

...volim muziku



...i dalje volim prirodu



...volim svog psa



...volim svoje unuke



Vidite to sam još uvijek

...volim svoj život



Ja...



i malo zaboravljam
ali nadam se da me vi
nećete zaboraviti.

Dementia at the time of Covid-19

Dementia at the time of Covid-19

Center for dementia Sarajevo
Osman Kučuk



Alzheimer association AiR

Amela Hajrić
Emina Kučuk



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Aida Pilav
Institute for Public Health Canton Sarajevo

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Introduction

This document was created in response to the current situation regarding the Covid-19 virus pandemic.

Drafting of this document is essential in order to help the relevant Ministries of Health and the Ministries of Labor and Social Policy to organize the protection of persons with dementia after WHO has issued recommendations for preventive measures to prevent large-scale epidemics and the Crisis Headquarters ordered movement bans, orders for self-isolation of unconfirmed cases of infection and mandatory isolation of confirmed cases of virus infection.

Namely, all the proposed measures by the Crisis Headquarters, Ministries and local governments bodies completely bypass and do not recognize persons with dementia but also their families and carers as vulnerable group, although, this population group is numerous. This violates their human rights and leaves them unsupported.

Therefore, with this document we want to bring dementia closer to the authorities and to provide them recommendations how can they do to help and facilitate to people with dementia who lives alone, with spouses or inside family. These recommendations need to draw attention on dementia issue, and on the first hand, help to all parties and facilitate these situation through reduce the number of bad and adverse outcomes. Also, the document can be printed and distributed as a guide to families with dementia affected person.

Osman Kućuk
Director of Center for dementia
ul. Tekija br. 52
71 000 Sarajevo
BiH
+387 33 200223
www.demencija.org

In regarding on the severity of entire situation and condition due to Covid-19 and passed bans as measures for protection of BH population, we want to pay attention on the next facts:

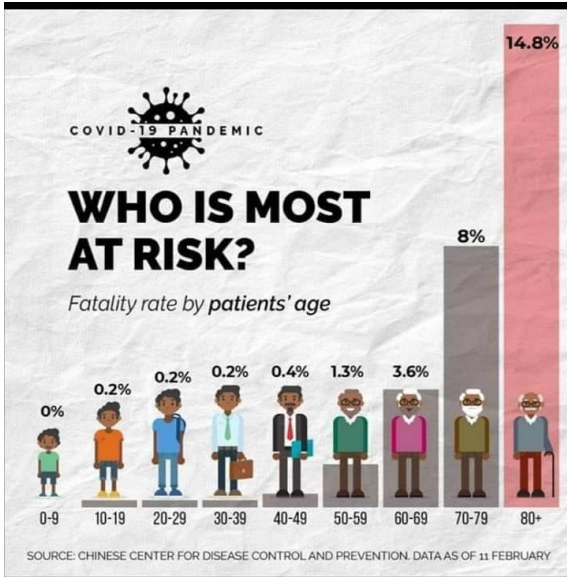


Figure 1

- The most risk for the fatality by the patient's age have people 50+
- Covid-19 is cause of death to every sixth affected person 80+



- Peoples with: cardiovascular diseases, diabetes, chronic obstructive respiratory diseases, high blood pressure and persons with carcinoma are groups with high risk for complications due to Covid-19 and in high percent ended fatality!

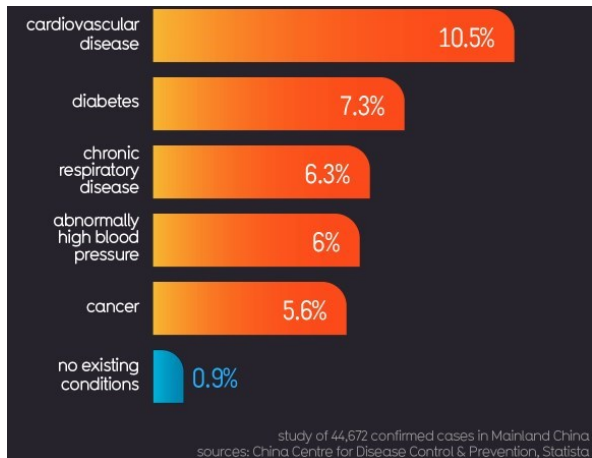
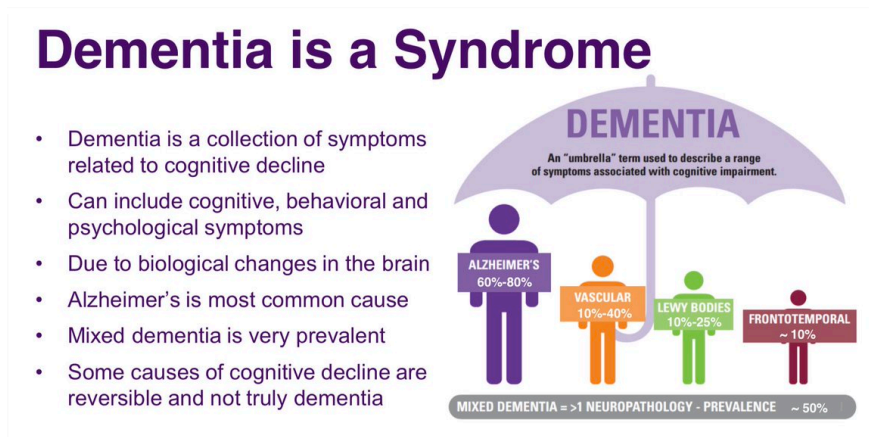


Figure 2

The passed measures of bans that were introduced to protect population and vulnerable groups, Government want to slow down spreading the Covid-19 that can provide adequate care and help to all infected peoples. But due to that decision in front of the Crisis headquarters, Ministry of health and social policies and entire society is the new obligation: "How to help and protect people living with dementia alone in their homes or with life partner"!

DEMENTIA

Figure 3



Dementia is not disease, it is a syndrome caused by other diseases. Dementia is a clinical syndrome characterised by the decline of previously acquired mental function that leads to a reduction or inability to perform daily activities. It is an acquired and permanent reduction of two or more intellectual functions. The development of the disease leads to changes in the person's behavior and loss of functionality and complete dependence on the other person, and in most cases these are the above mentioned risk factors. After Alzheimer's disease, vascular dementia bring the highest number of patients and caused by strokes that caused by: cardiovascular diseases, unregulated blood pressure, diabetes, atherosclerosis, etc. Infections, like cancer, cause cognitive

changes, drastically alter the disease or bring dementia. Infections worsen the condition of the affected person and complicate their overall psycho-physical condition which is maintained on their behavior.

CARE

Care of a person living with dementia implies the “Non Pharmacological Approach”, which is essentially program individually developed for each person and implemented by a multi-professional therapeutic team that working in collaboration with the medical multi-disciplinary team on a daily basis, improving the quality of life and slowing the progression of the disease and help to family to have a more functional member according to whom family has a fewer responsibilities. In BiH, such treatment of dementia is unknown and is not being applied (besides in Center for dementia). The family have a passive relation to their member affected by dementia as long as he/she has functionality and is independent from their help or he/she doesn't have unacceptable and disturbing behaviors that force the family to actively involved and participate in care.

Due to the duration of the disease, duration in most dementia 5-12 years after timely diagnosis, a person living with dementia (PWD) cannot be observe separately from caregivers who are in most cases spouses or their children with / without the help of informal caregivers. If the caregiver is a spouse then this is also an elderly person suffering from various illnesses and having health problems.

This category is, also, affected by various pressures that reflect on their psycho-physical fitness and health status. In any case, they are burdened with an enormous amount of stress due to: not knowing the course of the disease, not knowing how to manage the condition of the affected person, excessive hours spent with the affected person, not understanding by the others family members for their needs, etc.

Figure 4, One caregiver provide care for:

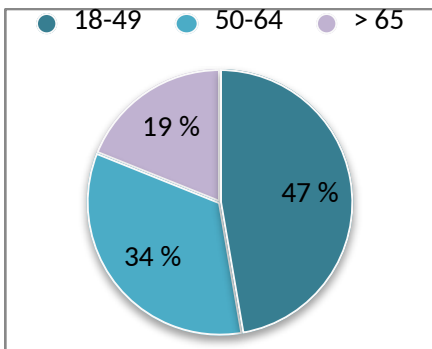
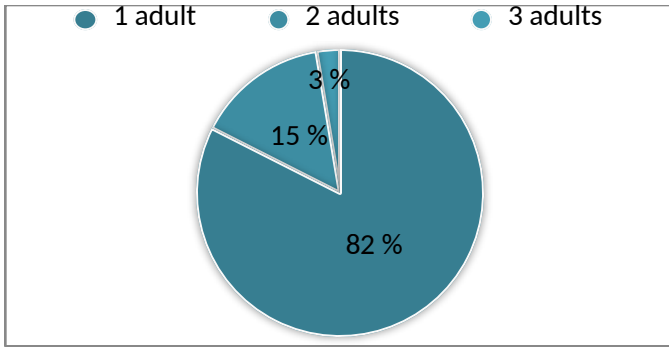


Figure 5 ; The age of caregivers

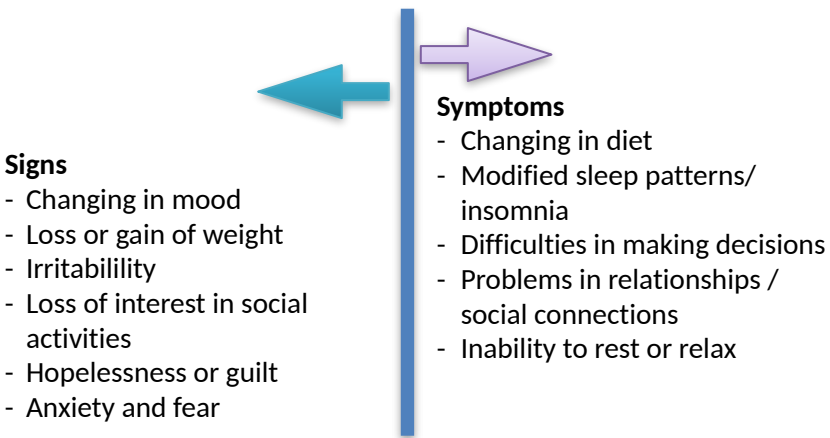
Figure 6



Caregivers provide help in more than 96% daily activities (such as help at personal hygiene, dressing the wardrobe) and in monitoring (taking medications, water, food...).



Signs and symptoms of „burnout at caregivers“ Figure 7



Načini prevencije „Izgaranja njegovatelja“

1. Recognize signs of stress and exhaustion
2. Make a schedule your activities and times
3. Maintain good health habits
4. Maintain social connections
5. Attending caregiver support groups
6. Maintain self-confidence
7. Follow an advices by psychotherapist
8. Make a deal for accommodation in respite homes for person with dementia. It is only temporarily (weekend...)



COVID - 19 and DEMENTIA

Covid-19 will not cause any type of dementia, but the overall condition will worsen if a person living with dementia becomes infected with the virus.

Figure 8

SYMPTOMS	COVID/19 Symptoms range from mild to severe	COLD Gradual onset of symptoms	FLU Rapid onset of symptoms	HAYFEVER	ASTHMA
FEVER >37,8°C	Common	Rare	Common	No	No
COUGH	Common (usually dry & continuous)	Mild	Common (Usually dry)	sometimes (Usually dry)	sometimes (Wheeze & cough)
SHORTNESS OF BREATH	sometimes	No	No	No	Sometimes
HEADACHE	sometimes	Rare	Common	Sometimes	No
SORE THROAT	Sometimes	Common	Sometimes	Itchy throat	No
STUFFY NOSE	Rare	Common	Sometimes	Common	No
SNEEZING	No	Common	No	Common	Rare
PAINS	Sometimes	Common	Common	No	No
FATIGUE	Sometimes	Sometimes	Common	Sometimes	No
DIARRHOEA	Rare	No	sometimes (for childrens)	No	No

As with any infection, the organism triggers a self-defense mechanism that is maintained on the overall human condition. Changes can be more or less visible and can be divided into individual and common.

Each person responds differently to the fight of an organism with infection. Very often, the layman is deceived by the good condition of the other person or even the affected person overlooks the obvious symptoms of the infection. Older people, people with chronic illnesses and people living with dementia will have no a different reaction on infection than they have endured previously.

REACTION ON INFECTION PERSON LIVING WITH DEMENTIA

1. Physical

- 1.a. Exhaustion
- 1.b. Slow motion
- 1.c. Dizziness
- 1.d. Difficulty getting up and walking

4. Behavioral

- 4.a. Aggressiveness
- 4.b. Violence
- 4.c. Agitation
- 4.d. Rejection
- 4.e. Apathy



2. **Psychic**

2.a. Anxiety

2.b. Depression

2.c. Bad mood

2.d. Hallucinations - possible

2.e. Illusions - possible

2.f. Insomnia / Somnolence



3. **Cognitive**

3.a. Puzzlement / Confusion

3.b. Difficult speech

3.c. Difficult understanding & expression

3.d. Disorientation - towards persons,
space, time

3.e. Difficult to perform even simple
actions

3.f. Movement problems

3.g. Recognition

PEOPLE WITH DEMENTIA THAT LIVE AT HOME:

1. Live alone

- a. Without a caregiver - extended independence
- b. Have the help / monitoring of an external caregiver

2. Living with spouse

- a. Without additional external help
- b. With help of external caregivers

3. Living in family

- a. Without external help
- b. With help of external caregivers



PROBLEMS IN IMPLEMENTATION OF ACTIVITIES AND MEASURES THAT ARE CONNECTED TO PRECAUTION FROM INFECTION WITH Covid/19

We are witnessing that the largest number of Covid-19 infections occurred when children or relatives were visiting a parent or elderly family member after their return from abroad - in the early stages of the epidemic in BiH. The reorganization of families after their joining to facilitate the organization and implementation of measures ordered by crisis headquarters at the time when the epidemic explodes in BiH will run the following issues:

- What to do and how the caregiver can protect themselves for their own sake and because of people with dementia,
- How to employ a third party if you're not sure that she was not pick up a virus during coming to your home,
- What if the caregiver or family member becomes infected, how to isolate and separate the person with dementia and how to arrange home care (where to find a new carer, how to let an unknown person into the house, how to pay for the service...),
- How to ensure that a person with dementia has everything they are used to having because you cannot explain the situation in the society and the restrictions they have raised.

These are not the only issues, but surely most of them produce frustration and increase the stress in the family that is transmitted to the person with dementia.

RECOMMENDATIONS FOR FAMILIES THAT HAVE PERSON WITH DEMENTIA

- a. If you notice that a person with dementia shows increased confusion, violence, etc. (see part of the reaction to the infection), contact your family doctor immediately and inform about the condition of PwD,
- b. Write reminders about how to wash hands and place reminders in a conspicuous position above a washbasin and sink
- c. Everyday PwD explain of hygiene measures for protection and prevention and if it needs several time in day
- d. Everyday show practical way and duration of handwashing and the way to protect the environment when sneezing / coughing
- e. Required to provide alcohol solution (min.60% alcohol) or disinfectant and spray hands of PwD after toilets or contact with others.
- f. Contact your family doctor and provide prescriptions and long-term medical therapies so you wouldn't go to the pharmacy often
- g. Make a backup plan in case one of your family members becomes infected with Covid / 19 to protect person and other family members

WHAT CAN WE EXPECT BY THE PERSONS WITH DEMENTIA(PwD) THAT LIVE ALONE OR WITH THE OCCASIONAL SUPERVISION OF ANOTHER PERSON:

- a. Not maintaining personal hygiene
- b. Failure to carry out a hygiene-epidemiological protocol when entering the home
- c. Not maintaining the household space clean and sterile
- d. Not to carry out measures of self isolation
- e. Not to carry out measures of physical distancing
- f. Failure to comply with collective barriers (curfew, ban on going out for the elderly ...)
- g. Spreading a virus infection beyond their volition
- h. Inadequate response to the situation in which is society

If the person with dementia BECOME INFECTED(Virus Covid-19) AND LIVES ALONE OR OCCASIONALLY HAS THE ASSISTANCE OF ANOTHER PERSON possible consequences could be:

- a. Dehydration
- b. Malnutrition
- c. Poorer health picture than expected
- d. Poor psychological condition
- e. A drastic cognitive decline that reflects on behavioral failures
- f. Premature death in unworthy conditions



HOSPITALIZATION DUE TO INFECTION WITH COVID/19 VIRUS

the condition of a person living with dementia will worsen rapidly in the all fields. With the expected worsening of the condition due to the onset of symptoms of infection on a person living with dementia will be further adversely affected by: new environment, unfamiliar environment and unknown persons and treatment of medical staff towards them, what they will interpret as violence against themselves. A set of all these factors will: prolong the number of hospital days, reduce the positive effects of medical treatment, contribute to faster cognitive decline of a person living with dementia. This cognitive decline, likely, will be permanent due to the lack of a rehabilitation system and insufficient knowledge of the staff involved in dementia care about the ways and the ability to recover and mitigate the effects of infection after healing. This will cause that the people who lived alone will lose that ability and will need 24/7 supervision and care by another person.

RECOMMENDATION: The ward that is determined for care of people with dementia need to have trained nurses for doing and communication with people with dementia and space have to be equipped with necessary equipment for providing an adequate activities. Person with dementia can't be alone in the room. It is best to group people with dementia and obligate the determined nurses for that groups. Involve volunteers for 24h monitoring. Special attention turn to daily fluid intake! During hospitalization, necessity are cognitive

exercising and physiotherapy activities adapted to the condition of the diseased person, and it is mandatory to use a decubital mattress.

RECOMMENDATIONS TO CANTONAL CRISIS HEADQUARTERS IN RELATION WITH:

Based on all of the above mentioned, we suggest that the Cantonal Crisis Headquarters of Civil Protection in cooperation with the Local Communities, the Cantonal Ministries of Health, the Ministries of Labor and Social Welfare, urgently create teams that will make lists of persons with dementia that are living alone, with their spouse or family. After creating a singular cantonal list, we suggest that you try to implement the following recommendations:

1. People with dementia who have a confirmed diagnosis, determined therapy and live alone in the household necessary is:
 - a. place in a collective center where they need to be provided with normal conditions of stay on a 24-hour basis. Accommodation in rooms with a maximum of 3 people. Toilet in the room. The Center should be able to carry out joint activities for that should be provided: physio therapists, work, occupational, art, music therapists, psychologists, social workers, medical technicians and a sufficient number of informal carers. The family physician should, at least once a week, reviewing all users, and he is obliged to come by the invitation from the Center.
 - b. alternatively, create teams composed of one nurse and a volunteer which they will be in charge with the own group of people with dementia and that will visit regularly and daily. During the visit, the nurse should measure the temperature and check the psycho-physical condition of the person, and carry out certain activities of cognitive training and physical-therapeutic activities. The volunteer is in charge for delivering of daily necessities, basic cleaning and disinfecting the home of a person with dementia.



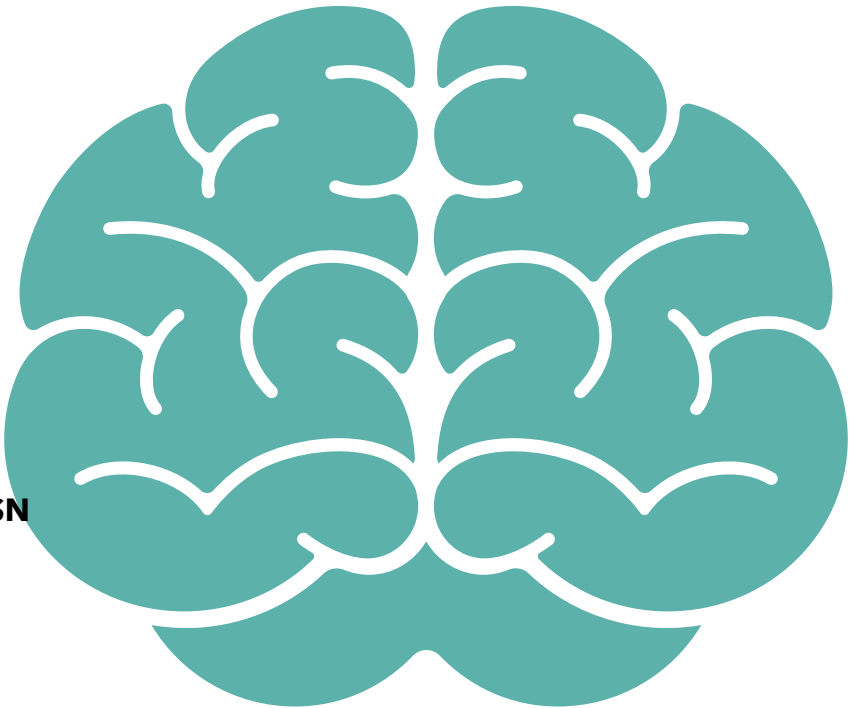
2. People with dementia who have a confirmed diagnosis, certain therapy and live with a family member infected with Covid-19
 - a. Organize a joint acceptance of an infected caregiver / family member and a person with dementia and place them in a unit for collective isolation. Do not separate a person with dementia from a family member who is infected. Also, do not leave a person with dementia and an infected carer / family member in a self-isolation!

Sarajevo; March 2020.



In Bosnia and Herzegovina live 150.000 persons with dementia!

ISSN



'I can live well with dementia'

1

I SHOULD HAVE ACCESS TO A DOCTOR TO CHECK IF I HAVE DEMENTIA.

I should have access to a memory assessment to check if my dementia worries are true. A diagnosis will allow my family, friends and I to plan for the years ahead and prepare for when my needs will change.



2

I SHOULD HAVE ACCESS TO INFORMATION ABOUT DEMENTIA SO I KNOW HOW IT WILL AFFECT ME.

Dementia will affect me and everyone around me. My family, friends and I should have access to high quality information and advice so we know what to expect as my condition progresses.



5

I SHOULD HAVE ACCESS TO HIGH QUALITY CARE THAT'S RIGHT FOR ME.

At all stages of the condition, I should have access to high quality care when I need it, be that in my home, my village, town or community, or in a care home.



4

I SHOULD HAVE A SAY IN THE CARE AND SUPPORT THAT I AM GIVEN.

I have a voice and should have a say in the care that I am given, for as long as I can.



3

I SHOULD BE HELPED TO LIVE INDEPENDENTLY FOR AS LONG AS I CAN.

I want to be as active as I can, for as long as possible, supported by those around me, in a safe environment.



6

I SHOULD BE TREATED AS AN INDIVIDUAL, WITH THOSE LOOKING AFTER ME KNOWING ABOUT MY LIFE.

People looking after me should know about my life, family and history so they can provide personalised care that's right for me. My care should be shaped around my personality, preferences and lifestyle.



7

I SHOULD BE RESPECTED FOR WHO I AM.

I should not be discriminated against on any grounds, including age, disability, gender, race, sexual orientation, religious beliefs, social or other status.



8

I SHOULD HAVE ACCESS TO MEDICINE AND TREATMENT THAT HELPS ME.

During all stages of dementia, I should have access to medication and treatment that helps me to live well, and these should be regularly assessed by my doctor.



10

I WANT MY FAMILY AND FRIENDS TO HAVE FOND MEMORIES OF ME.

I want to have peace of mind that my family and friends will have adequate support to cope with my death and be comforted in their grief, to help them remember me for the person I was.



9

MY END OF LIFE WISHES SHOULD BE DISCUSSED WITH ME WHILE I CAN STILL MAKE DECISIONS.

I should have a say about how I spend my final days, so my end of life care wishes should be discussed with me while I can still make decisions.

