ProAge

Preparation for Active Ageing

S.O.S.DEMENTIA

Cooperation against Alzheimer and Dementia

Curriculum

Budapest XV. District Municipality

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1. INTRODUCTION

The demographic turn and the age paradoxon

The social view on older age has significantly changed in Europe and North-America in the second half of the XXth century. The honour and respect, the taken for granted attitudes of earlier historical periods towards the elderly, was replaced by a radically different new social phenomenon appearing in the modern era of the globalized world and its welfare societies. In 1970 in her monumental work „ La Vieillesse", (The Coming of Age" in English version) Simone de Beauvoir intentionally broke the „conspiracy of silence" concerning the conditions and position of old people. She pointed out that „Old age is something like a shameful secret for the current society, it is not the subject of a polite discussion. It is not just the guilt of negligence but direct crime against the elderly. Old people are treated as outcasts of society behind the myth of economic development and abundance."[1] (Beauvoir 1972:6)

The answers for a basic question, whether the old age is a treasure or burden for societies and families are becoming more complicated in the XXI. century. The respect of the parents *(Honour your father and your mother)* was already written in the Ten Commandments of the Bible. The Indian culture and Chinese Confucian values, as well as the Islamic traditions also give great respect to the elderly. In the value system of the big religions old people and their life experiences are regarded with esteem. In the Greek and Roman culture the wisdom of the elderly was also highly appreciated. (Barabás 2013)

In this era, the loneliness, nuclear family, the single parenting, the single way of life, poverty, illnesses and the reverse socialization - when the younger teaches the older for the necessary digital knowledge and orientation, are the signs and symptoms of the changed environment around elderly people.

Well known facts are what the demography reflects: in modern societies citizens are getting older and older. The share of people over the age 60 has reached 25-34% in some "ageing societies".The statistical indicators underpin, that within these societies

[1] It is translated into English from the Hungarian publication so it may differ from the English translation of the French origin.

the share of old people increasing, as well as the average age of people, and most importantly, the increase of those years, in which old people can live in good health. From an economic and social policy point of view these demographic figures mean a serious headache for decision makers. By whom and how the resources can be created for the increasing and longer living of the elderly generation?

Viewing the eldely age from the individuls'perspective, it is not easy for the old person to retire after a long active life. The paradox of ageing is well described by Beauvoir: „Each human is subject to death and each of them think about it. Many of them are getting old but almost none of them are willing to face this embarassing change calmly. Nothing should be wanted more than retirement and yet, nothing is wanted least than old age."[2] (Beauvoir 1972:10)

In the process of ageing, the moment of retirement represents a dramatic event, because the former active years from one moment to an other, have to be replaced by a different way of life. In this new situation the share of duties and responsibilities is shrinking, the financial position is changing and the former personal contacts are becoming less frequent. This new situation could lead to depression, loneliness and to different mental and physical illnesses. The elderly age perceived by the majority of the societies is still a kind of undervalued stage of life.

Nevertheless, retirement could bring a new opportunity for the given generation. The seniors cannot be regarded as a homogeneous group. By the World Health Organisation's (WHO) grouping, between the age of 60-74, a person is considered to be elderly; between 75-89 years we talk of old age; between 90-99 years the very old age comes; and over 100 years one enters the age of Methuselah. Based on the definition of the WHO, the time of retirement in European societies coincides with the elderly age - as in the states of the continent the completion of labour market activity takes place between 60-67 years of age.

The process of getting old takes place in various ways and 'routes'. Elderly people themselves have different strategies in their new period of life. One is set to build a new

[2] See the previous footnote

career. The other possible option is a gradual withdrawal but still remaining active. The third one is giving up, a kind of drifting with life events. The last one is still a frequent pattern, many people cannot find their place in the family and in their communities after retirement. (Füzesi et al. 2013).

Understanding elderly age

At the beginning of the 20th century, the way of scientific approach about ageing and older generations has gone through some significant changes. An often cited model was the deficit model – which explained ageing not as a process but rather as a state of decline, and focused on the loss of abilities and skills of the elderly, both in the field of physical and of mental functions. This approach has become considerably marginalised in our day but the stereotypes pertaining to the model may still be encountered in ageing policies and in the communication concerning the elderly.

Another approach which has real significance and influence these days is the activity theory. It claims that after finishing the active period of their lives, elderly people are still in need of finding certain roles in their societies, communities and families. In order to be able to do that and to realise an active ageing they must preserve as many of their previous activities as possible. Activity and social participation are essential elements in the lives of the elderly.

The concept of active ageing gained a new sense in the WHO (World Health Organization) document - titled 'Active Ageing - Policy Framework' - prepared for the United Nation's Madrid World Assembly on Ageing in 2002. The document interprets active ageing as an opportunity for all the members of the retired generation to attain a physical, mental and social well-being, and to participate – according to their needs -, in all areas of social, economic, cultural and community life as well as in the support of their families, their immediate and extended environments. According to the approach of the WHO, the services and care improving the elderly's quality of life and actualising their safety are indispensable in order to attain the goal. (WHO, 2002)

The international political discourse on old age

The increasing number of elderly people, as well as the dilemmas related to ageing have been present in the political discourses of Europe and in the international organisations for more than 30 years.

The universal principles for elderly people (United Nations Principles for Older Persons 1991) lay down the protection of indenpendence during their whole life, the provision of social participation aiming at keeping the older adults integrated in society, the provision of care enabling them living in dignity and security and the value of self-fulfillment during their whole life. In the new century the UN has already adopted 5 world reports and several other updated presentations and forecasts on this theme. (World Population Ageing).

The EU declared the year 2012 as the European Year for Active Ageing and Intergenerational Solidarity. Other world organizations like the World Bank or the OECD put into the focus the emploment possibilites for older people with the provision of a flexible framework and non-discrimination environment. By the research of the EUROBAROMETER in 2012 one in every five european adult personally experienced ageism and age discrimination in the labour market. (Eurobarometer 2012).

During the last decades, several professional programs, action plans were born to influence the way of life in older age on local and national and international level. Each of them considers this period of life as valuable, worth developing both for the individual and the society. Preferred learning forms of the old people like elderly clubs, reading circles, learning circles, summer universities, folk high schools, camps, workshops, third age univerisites, community planning actions all built into the traditional practice of humanistic adult education. (Kleisz 2016)

Research on the old population covers several fields and themes: dementia and alzheimer, healthy diet, preventing falling down, supporting technologies and robots, loneliness, ageing on the countryside, social involvement of the elderly, poverty, discrimination, adequate elderly friendly living environment, etc. In the EU the

Horizon 2020 programme and its subprogram, the Health, Demographic Change and Wellbeing targets the sustainability of healthy way of life and the elderly care system. Research programs get support from the program to develop digital technologies to support the independent way of life of elderly people, permanent monitoring of their health status, the control of their food intake and provide personalized advice and care service for elderly.

Briefly about the ProAge „Preparation for Active Ageing" Erasmus+ project

Our project aimed to formulate a non-formal learning curriculum which presents good practices and innovative solutions for conscious preparation for active aging. These practices and activities are increasingly needed in ageing societies and are not - or hardly - accessible in formal learning materials. The project partners created a complex curriculum, which provides complex knowledge via domestic and international examples. It is suitable for civil organizations, elderly clubs, folk high schools, cultural institutions, libraries, and also for families and individuals who seek and want to achieve the individual 'routes' to old age. It is important that preparation for active ageing should take place consciously, adjusting to the characteristics of different generations and individuals.

An important goal is to avoid lagging behind and keeping pace with progress. The curriculum provides knowledge and experience in four important fields of life. The four modules of the curriculum can be used together as one volume. However, each of the modules can serve different target groups and different interests and can be used separately as well.

The first module is about IT teaching and learning in elderly age. There are a lot of courses available for IT. Our module's significant feature is that it pays special attention to the characteristics of learning in later life. The content and the teaching methods of the module are adjusted to their special needs and learning pace. The second module gives examples, best practices and instructions for all age-groups concerning voluntary activities. Participation in the life of the wider communities through volunteer activities is also important for elderly people as this domain helps to keep social ties with other persons and groups. This knowledge of participation in community life comes from

Norway. Community activities, and meeting with different generations is one of the best way to fight against loneliness and desperate depression. In order to pursue healthy way of life, to be active is very relevant for eldely people. The third module shares knowledge and provides advice on how to maintain or build up new habits for healthy lifestyle, useful leisure activities, nutritional advice and recreation possibilities. Slovenian experience presents physical activity patterns suitable for elderly. Also a healthy diet is an important ingredient of active ageing. The most threatening and still incurable illness for elderly people is demencia and its special form, the Alzheimer disease. The fourth module on this topic provides a lot of advice for family members how to adjust their life to this illness and how to make the progress of the illness bearable. The fourth module brings up several good practices on active ageing and the cooperation of generations as well as recommending what to do if it turns out that a family member lives with Alzheimer or Dementia.

The authors are convinced that each generation needs to pay attention to the upcoming period of life, not only those who are already in close proximity to retirement age.

What are the innovations in in our curriculum?

We consider that the whole approach, the selection of the themes of the curriculum, the proposed methods in each modules, the simple non-professional languge which can be understood by lay people, the structures of the modules, (starting from simple or basic issues towards more complicated ones), the community approach to the target groups, and the proposed community-based trainings (enforcing local democracy and the involvement of multiple generations) are the most important innovative features of the curriculum.

The selected themes cover 4 important aspects of life in old age. Bringing together the IT training, Volunteer activities, Handling Demencia and Alzheimer's and Activity can provide a good preparation for active ageing for different generations. It is not only the task of the 50+ generation close to retirement but it should start at an earlier stage of life, at least from the 30+ generation. Furthermore, the core idea of active ageing has to be acquired already in childhood via one's family life.

The preparation for active ageing requires a complex knowledge. Family members need to be prepared how to handle threatening illnesses, what social responsibility and volunteerism mean at an elderly age, and how to change learning patterns later in life. Therefore the preparation for active ageing needs a complex approach through different avenues. This knowledge has to become a basic value for the people involved, for local communities, families and multiple generations.

Kovács Dezső PhD. honorary professor

References

- Barabás Katalin (2013) Az időskor kultúrantropológiája. in: Kállai J. Kaszás B. Tiringer I. Az időskorúak egészségpszichológiája. Medicina Kiadó. 435p.
- Brettner Zsuzsa (2016) Elderly, caring for the elderly, dilemmas. In: Pilot project for quality ageing. Opening Conference publication. 22-26p.
- Füzesi Zs. Törőcsik M. Lampek K. (2013) Az időskor egészségszociológiája: tények és trendek. in: Kállai J. Kaszás B. Tiringer I. Az időskorúak egészségpszichológiája. Medicina Kiadó. 435p.
- Kleisz Teréz (2016) Az időskorúak tanulása. In: Az Aktív időskor és időskori tanulás nemzetközi konferencia válogatott anyaga. In: Tudásmenedzsment XVII. évfolyam 2. különszám 2016. december Pécsi Tudományegyetem http://kpvk.pte.hu/sites/kpvk.pte.hu/files/files/EKONYVEK/xvii2kulonszam_2016.pdf
- Simone de Beauvoir (1972): Az öregség. Európa könyvkiadó 862p.
- The 2018 Ageing Report. ISSN 2443-8014 (online) Underlying Assumptions & Projection Methodologies INSTITUTIONAL PAPER 065 | NOVEMBER 2017 The EU ECOFIN - - Dementia: A Public Health Priority (2012) WHO study
- https://www.inda.info.hu/uploads/dokumentumok/Haziorvosok_szerepe_web.pdf
- https://www.inda.info.hu/uploads/dokumentumok/demencia_kiadvany_A5_javitott.pdf
- https://www.inda.info.hu/uploads/dokumentumok/Kapaszkod%C3%B3k_2ik%20kiad%C3%A1s.pdf
- Minőségi élet 50+ Mintaprogram(Bilateral Activities in the Capacity Building and Institutional Cooperation. HU 11 .B1- 2017) www.manorquality.eu

1.1 INTRODUCTION

BUDAPEST, DISTRICT 15

District 15 of Budapest consists of three separate territorial units with different historical backgrounds: Rákospalota, Pestújhely and Újpalota. These territorial units are both architecturally and socially heterogeneous. It is moretrue for Újpalota, which is characterised by vast blocks of flats built in the 70s. With its detached houses in Rákospalota-Kertváros and the mixture of old-fashioned peasants' houses, blocks of flats and modern apartments in Öregfalu, Rákospalota is even less homogeneous. With its detached houses and villa-like buildings, probably Pestújhely is the most homogeneous part of District 15.

The district is the north-eastern gate of the capital. Thanks to the proximity of motorways M0, M2 and M3, the district has become attractive for large-scale commercial investments.

The district is 26,95 square kilometres. It has 137 kilometres of urban public road network of which 119 kilometres are paved. The sewerage system is 139 kilometres long. Population density is 2965 people per square kilometre.

In the last couple of years the population of District 15 of Budapest was around 80 thousand and it shows a slightly declining trend. According to the 2011 census, the population was **79,645**[3], on 1st January 2015, it was **80,327**, and two years later, it was **79,866** while on 1st January 2018 **78,111** people lived in the district.

The composition of the population follows the European and the Hungarian trend, the number of the elderly is slightly but continuously increasing while the number of births is stagnating. This may result in the ageing of the population in the long term. The number of elderly one-person households and the proportion of people living alone with different mental, health and social problems are increasing.

Demographic data demonstrate the ageing of the population thus the demand for elderly care is expected to increase which means enhanced demand not only for social assistance but also for health care services. Data also reveal that more than 19 percent of the district's population is older than 65.

[3] Hungarian Central Statistical Office:Data: October 2011

In cooperation with its partner NGOs the Local Government of District 15 has organised events recently by which it has gathered new knowledge about the elderly, particularly about those suffering from dementia.

With the involvement of the families, civil society activists and experts, the local government experimented with new methods in order to help people affected by the above mentioned condition (e.g. Beginning of the Third Life Stage – Professional Conference on Ageing; Nefelejcs Workshop: Presentations on Dementia; 'The Ageing Mind' – Conference for health care and social workers on the early recognition and treatment of dementia; accession to the Alzheimer Café network as Alzheimer Café Újpalota; establishment of a group for relatives; visit in Strasbourg; accreditation training in connection with dementia; publishing an information booklet on dementia; daytime service for people affected by dementia; Alzheimer Day – Professional Conference).

Dementia is unknown not only to the population but to the (social) service providers as well. Many people do not know that if these diseases are diagnosed early enough a lot can be done in order to mitigate symptoms thus helping families to cope with the situation. The cooperation among general practitioners, healthcare providers and social service providers is highly important.

During the compilation of the teaching material and the preparations a close relationship has developed among the local government, the healthcare providers, the social service providers and the members of the NGOs. The experience of the partner organisations has also been utilised in the material. The topics in each chapter are presented from several viewpoints. Besides theoretical knowledge, the teaching material also presents good practices of the professional work carried out in District 15 of the capital city.

Mrs. Ildikó Katonáné Jordáki who is an expert of the topic prepared the teaching material. She has a qualification in nursing and a degree in social work. She gained her professional experience as a mental hygienist in a nursing home where she dealt with people with dementia. Subsequently, she joined District 15's Joint Social Institution (ESZI) where she has been making use of his professional knowledge for years. The theoretical chapters also include the knowledge and experience gained through the decades.

1.2. Goal and Target Group

General goal of the teaching material is on the one hand to raise society's awareness of dementia via knowledge transfer and practical training, on the other hand to strengthen social values such as acceptance and tolerance towards people with dementia, their families and the caregivers. Further goals are to inform and support affected family members, collect and transfer their experience stemming from their own lives, process their experiences, ensure the autonomy and human dignity of the patients as long as possible.

With the involvement of experts and NGOs, it is also desirable to broaden theoretical and practical knowledge, strengthen interpersonal relationships and to create well-functioning and natural support.

Because of the openness and the outreach potential of the programme the teaching material considers not only the currently affected families but – for preventive reasons – also targeting the active generatio. Strengthening intergenerational cooperation is indispensable to raise awareness of the topic, considering the fact that the disease may affect younger generations as well within the family.

2. DEMENTIA

"It is a terrible and sweet gift that we are able to remember." (Endre Gyökössy)

According to a 2019 report of Alzheimer's Disease International (ADI) more than 50 million people live with dementia all over the world. By 2050, this number will have risen to 152 million. ADI estimates that the overall treatment of dementia costs 1 trillion dollars and this amount will have been doubled by 2030.[4]

Dementia is an umbrella term, which includes numerous diseases that change cerebration. People who suffer from dementia have impaired brain functions, difficulties in thinking, concentration and logical thinking. Their time and space awareness and their language skills also continuously deteriorate. One's self-sufficiency declines, then with the aggravation of the disease it completely ceases.

Dementia is incurable but the early recognition of the disease is indispensable because an early drug therapy can slow the course of the disease and mitigate behavioural disorders as well. The quality of patients' life can be improved and personal autonomy can be preserved for a longer period. Dementia affects not only the patient but also his/her direct environment as well placing a significant burden on the families.[5]

2.1. Types of Dementia

Dementia is a syndrome that is always a result of brain lesions. These lesions appear gradually in the symptoms. Symptoms may include blackout, difficulty in thinking, deterioration in problem solving ability and language skills. These symptoms severely limit the capabilities of the affected people. The memory loss present in the early stage of dementia should not be mixed up with old-age forgetfulness.[6] This chapter would like to help the affected people, the families,

[4] World Alzheimer Report 2019 (2019), p.13.
https://www.alz.co.uk/research/WorldAlzheimerReport2019.pdf Downloaded on 29/10/2019
[5] Magyar Gerontológia 2010 , nr.7.(July)
http://foh.unideb.hu/sites/default/files/upload_documents/magyar_gerontologia_2.7.pdf Downloaded on 18/07/2019;
Cayton–Graham–Warner, 2006.
[6] https://www.felejtek.hu/mi-a-demencia.html Downloaded on 18/07/2019;
Cayton–Graham–Warner (2006)

the caregivers who intend to deepen their knowledge in connection with dementia and the related diseases.

Figure 1: Dementia as an umbrella term[7]

2.1.1. Dementia Triggered by Alzheimer's Disease

The most common form of dementia is Alzheimer's disease, which was described by Alois Alzheimer in 1906. This disease goes along with the death of neurons and characterised by a gradual mental decline which is accompanied by psychological and behavioural symptoms. The vast majority of people suffering from Alzheimer's disease is over the age of 65 but there are younger patients as well.

With the help of diagnostic imaging, (X-ray, CT or MRI) minor plaques can be detected on the projections of the brain neurons. These lesions hinder information transfer among cells. The first step in the process is that neurotransmission ceases among cells, then the neurons die. Serious deterioration can be observed in the mental abilities of the patients suffering from the disease that makes them unable to live normally.

[7] Site of the Affected People and the Supporters Fighting Against Alzheimer's Disease or Other Types of Dementia (ADÉL)

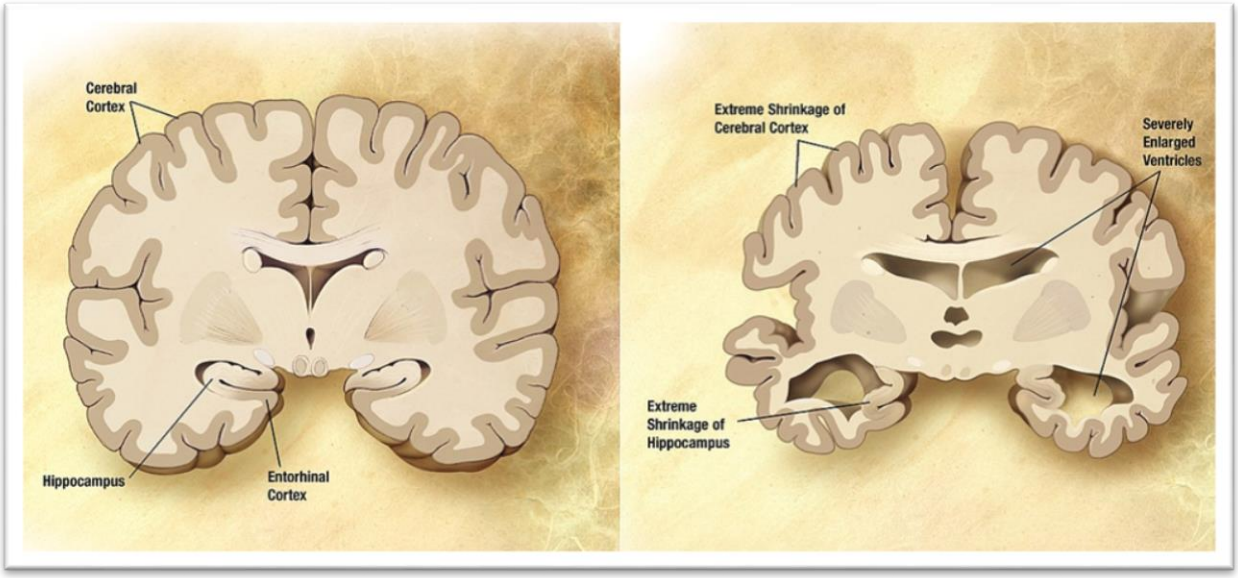

Figure 2: Comparison of a healthy brain on the left with an ill brain with Alzheimer's disease on the right[8]

Typical symptoms of the disease:

- the most common symptom is that the patient is not able to evoke new information, to learn new things,
- fatigue,
- short-term memory loss (e.g. right after the meal patient cannot remember what he/she ate, or that he/she even ate at all, forgets where he/she has put things, etc.),
- communication difficulties,
- difficulties in finding the proper words,
- then speech comprehension problems may occur,
- writing and reading gets harder,
- patient is not able to name certain objects, the use of these objects is problematic (e.g. unable to use the remote control of the TV),
- coordination impairments occur,
- patient's appetite changes,
- sleep disorder occurs,
- difficulty in getting dressed independently,
- temporal and spatial disorientation occurs (e.g. patient is not able to tell which city he/she is in, gets lost on a familiar route, unable to name season, year, month or day),
- mood swings occur (e.g. depressive mood or nervousness, excitement, stress),
- hygiene of the patient deteriorates,

[8] https://hu.wikipedia.org/wiki/Alzheimer-k%C3%B3r Downloaded on 30/10/2019

- alteration in personality and behaviour may occur,
- patient becomes unmotivated,
- patient's comprehension skill deteriorates,
- patient's self-sufficiency declines as the disease progresses,
- dysphagia may occur.

With the progression of the disease symptoms become more severe. In the severe phase of the disease the patient may need full care and may become bedridden.[9]

2.1.2. Vascular Dementia

The term 'vascular dementia' was coined by a German psychiatrist Emil Kraepelin who claimed that the disease is the consequence of cerebral circulatory disturbances (e.g. stroke) which lead to a decline in cognitive and thinking activities (cognitive functions such as attention, memory, perception, problem solving, learning, making a decision, calculation, use of languages, etc.). Due to the calcification of the blood vessels, cells do not get enough oxygen-rich blood, which results in the death of brain cells.

Vascular dementia mostly develops suddenly making the patient's condition volatile. A gradual decline of the condition characterises the course of the disease.

The most typical symptom:

Symptoms occur depending on which area of the brain has been affected by the disease:

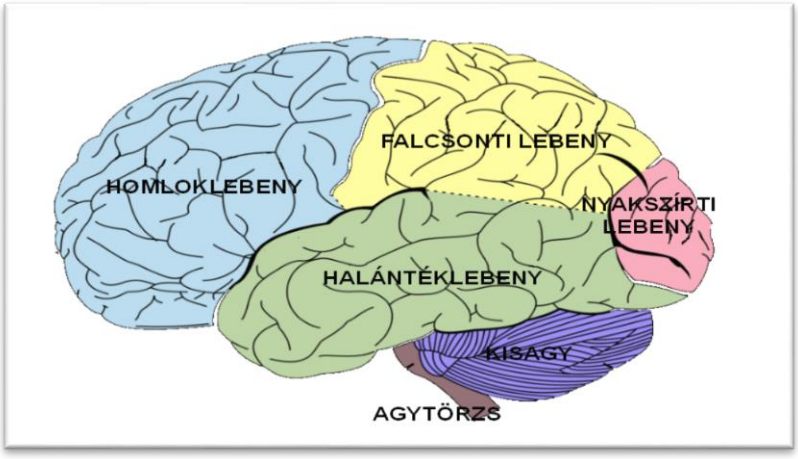

Figure 3: Lateral view of the left hemisphere of the brain[10]

[9] Magyar Gerontológia 2010.nr.7.
http://foh.unideb.hu/sites/default/files/upload_documents/magyar_gerontologia_2.7.pdf, Downloaded on 18/07/2019;
http://www.miet.hu/hir/39459/alzheimer Downloaded on 18/07/2019;
Cayton–Graham–Warner, 2006

[10] https://hu.wikipedia.org/wiki/Agyf%C3%A9ltek%C3%A9k Downloaded on 20/09/2019

Damage to the temporal lobe (green) results in problems with understanding and memory, difficulties in processing sound stimuli, word-finding difficulties, partial loss of the sense of smell.

Damage to the parietal lobe (yellow) results in coordination impairments, disorientation, and difficulties in recognising objects.

Damage to the frontal lobe (blue) results in difficulties in thinking, planning, speaking and self-expression. Reduction in the ability to voluntarily move skeletal muscles occurs, just like alteration to personality and behaviour.

Damage to the occipital lobe (lilac) results in impairment of processing visual stimuli.[11]

2.1.3. Diffuse Lewy Body Disease

Harmful deposits of protein bodies (Lewy bodies) appear in the neurons. The condition of the patient is volatile, the symptoms may change on a daily basis according to the level of protein within the neurons.

Typical symptoms of the disease:

- a typical symptom is visual hallucination (the patient perceives non-existing things),
- coordination impairments,
- sluggish movement,
- shuffling,
- trembling limbs,
- memory disorder,
- attention deficit disorder,
- difficulty in making decisions.[12]

[11] https://www.dementia.org.au/files/helpsheets/Helpsheet-AboutDementia01-WhatIsDementia_hungarian.pdf, Downloaded on 08/18/2019;
http://idosgyogyaszat.hu/upload/idosgyogyaszat.hu/files/131215_A_vascularis_dementia_es_a_leggyakoribb_tarsbetegsegek_terapiaja.pdf, Downloaded on 08/18/2019;
Cayton–Graham–Warner,2006

[12] https://www.mayoclinic.org/diseases-conditions/lewy-body-dementia/symptoms-causes/syc-20352025, Downloaded on 20/07/2019;Tringer,2010Cayton–Graham–Warner,2006)

2.1.4. Mixed Dementia

Mixed dementia means the simultaneous presence of more than one type of the disease. In general it is the combination of Alzheimer's disease and vascular dementia or Alzheimer's disease and Lewy body dementia.

Typical symptoms of the disease:

- memory disorder, mainly short-term memory is damaged,
- temporal and spatial disorientation,
- word-finding difficulties,
- aphasia,
- mood swings, depression,
- loss of motivation,
- anorexia[13]

2.1.5. Frontotemporal Dementia (FTP), Niemann-Pick Disease

This rare disease was first described in 1892 by Arnold Pick. Frontotemporal dementia means the atrophy of the frontal lobe. The disease affects a certain part of the brain where so called Pick cells appear causing damage to the brain cells. This is a rapid course disease.

Typical symptoms of the disease:

- Symptoms appear relatively early, from around age 40 to 60,
- at the outset word-finding difficulties can be observed,
- aphasia: patient continuously repeats words (perseveration),
- behavioural disorder (e.g. inconsiderate, uninhibited, insensitive behaviour),
- uncontrolled eating,
- depression,
- regular traipsing,
- conduct disorder,
- inflexible thinking,
- compulsive behaviours,
- neglect of hygiene,

[13] https://www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia/mixed-dementia Downloaded on 18/07/2019;
Cayton–Graham–Warner,2006

- coordination impairments,
- dysphagia when eating,
- in the severe phase of the disease: aphasia and urinary incontinence,
- the course of the disease is about 7 years.[14]

2.1.6. Parkinson's Disease

The disease was diagnosed by and named after James Parkinson who described it as 'trembling' paralysis. Symptoms may occur even at the early old age.

The area in the brain which is responsible for fine motor movement is damaged. In Parkinson's disease tremor, muscle stiffness or muscle weakness occur at first, while later problems with recognition and thinking and also cognitive disorders (e.g. perception, attention, memory, etc.) can be observed.

Typical symptoms of the disease:

- shaky hands at the outset, later whole body tremor,
- coordination impairments,
- muscles become stiff (e.g. limbs cannot be completely stretched),
- slowness of speaking, thinking and moving,
- sleep disorder,
- memory disorder,
- dysphagia,
- mood swings, depression (frequent crying),
- attention deficit disorder.[15]

[14] https://hu.easymedicaldiagnosis.com/generalizovannaja-cerebralnaja-atrofija-2-stepeni.htm Downloaded on 18/07/2019
https://www.webbeteg.hu/cikkek/demencia/14913/a-pick-betegseg Downloaded on 18/07/2019
Cayton–Graham–Warner,2006
[15] https://www.drdiag.hu/kereso/diagnosztika.adatlap.php?id=93523&name=Demencia-Parkinson-k%F3rban-%0D Downloaded on 18/08/2019
https://www.webbeteg.hu/cikkek/demencia/22441/a-parkinson-koros-demencia-es-a-lewy-test-betegseg
Downloaded on 18/08/2019

2.1.7. Huntington's Disease

This rare genetic disorder was named after George Huntington. Symptoms occur between the ages of 40 and 50.

Typical symptoms of the disease:

- the very first symptom is eye movement disorder,
- with the progression of the disease chorea occurs,
- unsteady gait,
- depression may occur,
- memory disorder and slow thinking,
- changes in personality (e.g. patient becomes suspicious),
- changes in behaviour (e.g. violent outbursts, aggressiveness, lack of self-control).[16]

2.1.8. Creutzfeldt-Jakob Disease

Creutzfeldt-Jakob disease is very rare and it belongs to the group of prion diseases. Prions are special proteins in the human body. In Creutzfeldt-Jakob disease these proteins go through a modification process and they damage the brain. Due to the death of the cells parts of the brain may resemble a sponge.

Types of the disease:

- sporadic type occurring around the age of 60-65,
- hereditary type,
- acquired form, type 1: transmitted via infected medical tools during medical intervention,
- acquired form, type 2: transmitted via the consumption of beef infected by bovine spongiform encephalopathy (so called mad cow disease).

Typical symptoms of the disease:

- memory disorder and aphasia,
- concentration deficit disorder,
- enhanced irritability,
- visual disturbance (e.g. diplopia),

[16] http://www.parkinson-tarsasag.hu/upload/parkinson/document/jakabkat.htm, Downloaded on 18/07/2019

- insomnia,
- coordination impairments,
- tremor in the limbs, involuntary movements (chorea),
- epileptic seizures.[17]

2.2. Reversible Dementias

Dementia is an incurable disease. There are some diseases that may also bring about the symptoms of dementia, however after the elimination of the root cause, dementia can be stopped, in some cases it is reversible.

2.2.1. Wernicke-Korsakoff Syndrome

Wernicke-Korsakoff syndrome is a secondary alcoholic dementia caused by the lack of vitamin B1 (thiamine). After the complete cessation of alcohol consumption and after the supplementation of vitamin B1 the disease is 25 per cent curable.

Typical symptoms of the disease:

- frequent diplopia,
- unsteady gait,
- coordination impairments,
- unsteady gait, in severe cases inability to walk,
- temporal and spatial disorientation,
- confusion,
- aggressive behaviour,
- nonchalance,
- memory disorder.[18]

2.2.2. Normal Pressure Hydrocephalus

Under normal circumstances brain produces liquid (liquor cerebrospinalis) which protects the brain and the spinal cord from external physical damages. Normal pressure hydrocephalus occurs when cerebrospinal fluid gets accumulated in the brain ventricles without pressure

[17] https://www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia/creutzfeldt-jakob-disease; https://www.webbeteg.hu/cikkek/demencia/21147/creutzfeldt-jakob-kor, Downloaded on 18/07/2019

[18] https://www.tankonyvtar.hu/hu/tartalom/tamop425/2011_0001_524_Neurologia/ch02s06.html Downloaded on 01/10/2019
https://www.verywellhealth.com/normal-pressure-hydrocephalus-98842 Downloaded on 01/10/2019

increase. By draining the water surplus via surgery the condition of the patient may improve or the disease may even disappear.[19]

2.2.3. Lack of Vitamin B12

Vitamin B12 belongs to the group of water-soluble vitamins and it is essential for the human body. It can be ingested via food or injected in a vaccine.. Vitamin B12 can be found in pork liver, beef liver, dairy products and herring. The recommended daily intake for adults is 2 micrograms. With the supplement of the vitamin mental problems may cease.[20]

2.2.4. Thyroid Disease

Thyroid is an endocrine gland which produces hormone. It is located on both sides in front of the trachea and the larynx. Low level of hormone production means that the thyroid is underactive which is called hypothyreosis. The disease can be cured by appropriate drug treatment thus the dementia – as a consequence of the disease – is reversible.[21]

2.2.5. Side Effects and Drug Interactions

Drug interactions may occur when a patient needs to take more drugs simultaneously because of a certain illness. This may bring about the symptoms of dementia. Once drug interactions are eliminated, symptoms of dementia become reversible.[22]

2.2.6. Brain Tumours

Brain tumours (such as slowly evolving meningioma) apply pressure on the affected part of the brain resulting in the occurrence of the symptoms of dementia (e.g. memory disorder, poor judgement, personality change, etc.). Some tumours can be removed via surgery or the patient's condition can be improved by different types of treatments (chemotherapy, radiation therapy) thus dementia can be reversed.[23]

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[19]Kordas, 2002. http://aok.pte.hu/docs/phd/file/dolgozatok/2002/Kordas_Mariann_tezisfuzet.pdf Downloaded on 01/10/2019

[20] https://www.webbeteg.hu/cikkek/egeszseges/3714/amit-a-b12-vitaminrol-tudni-kell https://www.verywellhealth.com/is-it-alzheimers-disease-or-vitamin-b12-deficiency-98738 Downloaded on 01/10/2019

[21] https://www.verywellhealth.com/normal-pressure-hydrocephalus-98842 Downloaded on 01/10/2019 https://www.webbeteg.hu/cikkek/endokrin/12572/pajzsmirigy-betegseg-es-tunetei Downloaded on 01/10/2019

[22] https://www.verywellhealth.com/normal-pressure-hydrocephalus-98842 Downloaded on 01/10/2019

[23] https://www.verywellhealth.com/normal-pressure-hydrocephalus-98842 Downloaded on 01/10/2019

2.2.7. Subdural Hematoma

Haemorrhage occurs between the dura mater and the brain which can be the consequence of broken blood vessels or an external trauma (e.g. bruise within the cranium).

Haemorrhage may occur:

- abruptly (acute subdural hematoma),
- in the form of a slowly evolving subdural hematoma (subacute subdural hematoma),
- in the form of chronic subdural hematoma (subdural hematoma),
- Dementia becomes reversible after the disappearance of the hematoma.[24]

2.3. The Classification of Dementia by Localisation

According to the location of the disease two types can be distinguished: cortical dementia and subcortical dementia. The two areas of the brain have different functions.[25]

2.3.1. Cortical Dementia

The external part of the cerebral cortex is the grey matter. The cells of the grey matter are responsible for the detection of stimuli. Diseases which are affected by cerebral cortex are Alzheimer's disease, vascular dementia and Diffuse Lewy body disease.

Typical symptoms of cortical dementia:

- thinking capability becomes affected in the early stage of the disease,
- patient is unable to name objects, he/she has difficulties in recalling words,
- aphasia,
- patient is unable to recognise faces or familiar objects,
- difficulty in using simple tools or devices,
- difficulty in getting dressed independently,
- short-term memory disorder,
- gradual deterioration of long-term memory,
- patient behaves indifferently.[26]

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[24] http://semmelweis.hu/igazsagugy/files/2012/06/18_mszlev.pdf Downloaded on 01/10/2019
https://www.verywellhealth.com/normal-pressure-hydrocephalus-98842 Downloaded on 01/10/2019

[25] https://www.tankonyvtar.hu/hu/tartalom/tamop425/2011_0001_524_Neurologia/ch02s05.html Downloaded on 01/10/2019
https://esem.hu/szotar/feherallomany Downloaded on 20/07/2019

[26] https://www.tankonyvtar.hu/hu/tartalom/tamop425/2011_0001_524_Neurologia/ch02s05.html,
https://esem.hu/szotar/feherallomany Downloaded on 20/07/2019

2.3.2. Subcortical Dementia

White matter is located beneath cerebral cortex and it is responsible for stimulus transmission. Diseases which affect cerebral cortex are Huntington's disease, Parkinson's disease, AIDS dementia and supranuclear palsy.

Typical symptoms of subcortical dementia:

- disturbed and slowed thinking,
- word-finding difficulties,
- nasal speech which is difficult to understand,
- deteriorated articulation,
- difficulties in recognising familiar objects or faces,
- need for help to recall short-term memories,
- long-term memory remains,
- personality disorder,
- apathetic behaviour,
- depression,
- unsteady gait,
- shaky hands,
- involuntary jerking movements which may concern the whole body,
- pathological posture.[27]

2.4. Stages of Dementia

The course of disease and the severity of symptoms vary from patient to patient. It takes a long time for the first symptoms to develop after the appearance of the lesions in the brain. The following three stages can be distinguished after the development of the symptoms: initial stage, moderate stage, severe stage.

[27] Tringer, 2010 Szirmai,2011.
https://www.tankonyvtar.hu/hu/tartalom/tamop425/2011_0001_524_Neurologia/ch02s05.html, Downloaded on 20/07/2019
https://esem.hu/szotar/feherallomany, Downloaded on 20/07/2019

2.4.1. Initial Stage

Slight decline occurs in this stage.

Discernible symptoms:

- short-term memory begins to deteriorate but the patient is able to recall bygone memories,
- difficulties in remembering the content of books,
- patient's attention can be drawn and diverted and it can also be engaged for a long time,
- difficulties in carrying out mathematical operations which were carried out easily before,
- word-finding difficulties,
- patient recognises relatives but he/she may not remember their names immediately,
- patient perceives the passage of time poorly or does not perceive it at all,
- patient puts objects to improper places (e.g. glasses into the fridge),
- refrains from making important decisions,
- patient gets lost when travelling,
- anxiety and depression,
- patient is still able to recognise and meet his/her needs,
- close monitoring is not (yet) needed.[28]

2.4.2. Moderate Stage

Moderate decline occurs in this stage.

Discernible symptoms:

- forgetfulness, difficulties in recalling the memories of the recent past,
- difficulties in carrying out mathematical operations (test: counting back with 7),
- temporal (patient is unable to name years, days, weeks, months or seasons properly) and spatial (patient is unable to define his/her location) disorientation,
- patient is able to recognise his/her relatives, but not always able to recall the names of people he/she rarely meets,
- patient often gets lost (traipses aimlessly),
- difficulties in fulfilling more complex tasks, patient's thoughts are unfocused,

[28] https://inda.info.hu/uploads/dokumentumok/interprofesszion%C3%A1lis_demens_ell%C3%A1t%C3%A1s%20alternat%C3%ADv%C3%A1i.pdf, Downloaded on 14/07/2019

- patient's attention can be drawn and diverted, but it can be engaged only for a short time,
- aphasia,
- personality change manifesting in behavioural and other mental disorders such as aggressiveness, excitement or restlessness (e.g. patient continuously puts clothes into and takes them out from the wardrobe),
- patient is not any more interested in his/her hobbies,
- patient is less willing to reach a compromise,
- stereotypical storytelling (patient repeats the same stories for the umpteenth time),
- patient is just partially self-sufficient,
- patient needs assistance in carrying out basic activities such as cooking, tidying, shopping,
- patient organises the meal on the plate (e.g. he/she separates rice from the peas when eating rice & peas),
- patient has money management problems (unable to recognise the value of money), engages in uncontrolled purchases, also often piles up goods,
- patient easily becomes a victim of tricksters because of his/her distorted judgement,
- patient is in need of assistance to recognise his/her own hygienic need (e.g. bathing, using the toilet),
- patient needs help in dressing up (e.g. he/she does not always find seasonal pieces of clothes or shoes),
- coordination impairments occur resulting in frequent falls,
- patient needs instructions and MAY ALSO NEED SUPERVISION![29]

2.4.3. Severe Stage

This stage is characterised by severe decline:

- severe memory loss occurs,
- complete spatial and temporal disorientation,
- patient is not always able to recognise her relatives; sometimes for instance she mixes up her son with her husband or father.
- patient's thinking is disorganised due to the lack of planning or evoking abilities,
- patient does not know what is going on around him/her,

[29] https://inda.info.hu/uploads/dokumentumok/interprofesszion%C3%A1lis_demens_ell%C3%A1t%C3%A1s%20alternat%C3%ADv%C3%A1i.pdf Downloaded on 14/07/2019

- aphasia,
- patient is not able to travel alone, he/she gets lost,
- coordination impairments occur resulting in frequent falls,
- in severe cases patient may lose his/her ability to move,
- as a consequence of bedridden status specialised nursing tasks may need to be fulfilled (e.g. bedsore may occur),
- sleep disorder,
- patient becomes incapable of self-sufficiency,
- incontinence may occur,
- patient needs assistance in eating, may also has to be fed,
- the risk of dehydration increases because the patient does not care about fluid intake,
- apathy or agitated behaviour occurs,
- PATIENT NEEDS FULL CARE (hygiene, feeding, dressing up).[30]

2.5. Symptoms Related to the Lobes

Cerebral lobes have already been discussed in the chapter dealing with vascular dementia (frontal lobe, temporal lobe, parietal lobe, occipital lobe and the insula enclosed by frontal and temporal lobes). Symptoms related to cerebral lobes occurring with dementia are described below:

Autotopagnosia:

Patient with dementia ignores a certain half of his/her body.

Anosognosia:

Patient ignores lesion, for instance the paralysis on the left side, or he/she is not able to distinguish between his/her left and right hand sides.

Acalculia:

Patient will not be able to carry out mathematical operations of which he/she was able to before.

Agraphia:

Patient is unable to write down words continuously.

[30]https://inda.info.hu/uploads/dokumentumok/interprofesszion%C3%A1lis_demens_ell%C3%A1t%C3%A1s%20alternat%C3%ADv%C3%A1i.pdf Downloaded on 14/07/2019

Alexia:

When reading, patient alters syllable order or uses synonyms of the given words instead.

Apraxia:

Patient is not able to carry out certain movements because of the damage to the movement planning ability. If the left side of the parietal lobe is damaged both sides are affected. While if the right side of the parietal lobe is damaged only the left limbs lose their capability to move.

Aphasia:

It occurs when comprehension skills in the temporal lobe and the motor speech centre in the frontal lobe are damaged. **Motor aphasia** means that the patient can understand speech, responds to instructions but cannot express him/herself. Patient's speech falters, grammatical errors occur. **Sensory aphasia** means that patient's speech is not understandable at all, and he/she is not able to act in accordance with the given instructions. If the patient does not understand speech and he/she is unable to speak as well, we call that **global aphasia**. When the patient suffers from **anomic aphasia** he/she often paraphrases objects because he/she is unable to name them. In **semantic aphasia** patient is unable to name objects or to identify words.[31]

2.6. Behavioural and Psychological Symptoms of Dementia (BPSD)

BPSD occur in nearly every type of dementia and they vary according to the type and stage of the disease. Some patients show the signs of behavioural alterations that did not characterise them before (swearing, shoplifting, collecting things, becoming messy etc.). With the progression of the disease changes in personality and behaviour become more severe. Thus the relatives may feel very uncomfortable in certain situations. The patient suffering from dementia is not responsible for the unpleasant changes in his/her behaviour. It is important to stress that the patient is not intended to annoy his/her caregiver or relatives who have to learn how to handle these situations. As everyone is different, every family that is affected by dementia has to cope with different problems in the course of the disease.[32]

[31] http://neurosurgery.pote.hu/idegseb/dat/isebjegyzethu/f4.html Downloaded on 15/10/2019
[32] https://inda.info.hu/uploads/dokumentumok/pszichopatologia.pdf Downloaded on 19/07/2019

2.6.1. Behavioural Disorders

Typical behavioural disorders in the course of dementia:

Agitation:

Agitation is a behaviour which denotes socially inappropriate actions.

According to the 1986 categorisation of Cohen-Mansfield and Billing there are four forms of agitation:

1. Verbally agitated non-aggressive form:

Patient repea

2. Physically non-aggressive:

Patient aimlessly wanders around, piles up unnecessary things or does socially unacceptable activities (e.g. urinates in public).

3. Physically aggressive:

Patient behaves aggressively, for instance he/she spits, tweaks, kicks, bites or scratches.

4. Verbally aggressive form:

Patient shouts, screams, swears or scolds.

Aggression:

Patient may display self-harming forms of behaviour such as scratching until bleeding (without itching). Passive, indirect physical aggression also often occurs. Patient rejects food and drink.

Delusion:

Delusion means that the patient has pathological misconceptions. The most common case is when the patient cannot remember where he/she put things and thus accuses others with theft.[33]

2.6.2. Psychological Symptoms

The following psychological symptoms may occur with dementia:

Anxiety:

Anxiety means fear without identifiable reason.

[33] Tringer (2010)
https://inda.info.hu/uploads/dokumentumok/pszichopatologia.pdf Downloaded on 20/07/2019
http://neurosurgery.pote.hu/idegseb/dat/isebjegyzethu/f4.html Downloaded on 20/07/2019

Apathy:

It is a very frequent problem for people with dementia. The symptoms of apathy can easily be confused with depression. While nonchalance of depressive origin is accompanied by mood swings, apathy has nothing to do with mood swings, only indifference and the lack of motivation occur.

Mood swings, depression:

In the course of dementia – particularly in the initial stage – symptoms of depressive mood swings occur accompanied by serious anxiety. The patient suffers from bad mood and lack of motivation, he/she neglects him/herself (hair, clothing), his/her social relations, tidying or cooking. It may also happen that the patient threatens with or fantasises about committing suicide. The appearance of the symptoms mentioned above means considerable psychic burden for the relatives and/or the caregiver of the person who lives with dementia. Symptoms are avoidable, or – after their development – they can be cured by medicine. Close cooperation with an expert (psychiatrist) is indispensable. Changing the prescribed medicine belongs to the competence of the doctor, the caregiver is not allowed to do so.

Hallucinations:

Hallucination occurs in the absence of stimuli. This is a pathological delusion when the patient sees non-existing things and also able to give detailed description of the perceived things (the clothes of the one he/she has'sawn'). Hallucinations occur most frequently in the Lewy body dementia. At the appearance of the delusion the patient insists on what he/she has imagined. One of the most frequent delusions is when the patient accuses his/her caregiver or relative with theft. This may cause a lot of conflicts within the family.

Misidentification:

Misidentification goes along with pathological thoughts. The most common manifestations of misidentification:

- patient imagines another person in his/her home,
- person with dementia does not recognise his/her own reflection, thus he/she may even talk to him/herself,
- patient experiences the scenes in the television as reality (this is particularly dangerous with violent or horror movies).[34]

[34] Tringer(2010)
https://inda.info.hu/uploads/dokumentumok/pszichopatologia.pdf Downloaded on 20/07/2019

3. THE RECOGNITION OF DEMENTIA, FACING THE DISEASE

People are said to be diverse. With a wide variety of experiences, insignificantly few or many problems, general or specific symptoms, completely general or unique behaviours. It is difficult to generalize that at a given moment how a particular person or persons respond to a signal, to the difficulties of the daily routine, or to an abnormal behavioural change.

Figure 3: Three monkeys (do not look, do not listen, and do not speak)[35]

This picture is a good depiction of the three possible human attitudes toward abnormal behaviour and otherness. Many people see the slow change and the abnormal behaviour nonetheless they do not want to take notice of them. There are people who do not want to hear, to see or to take notice of the complaint despite the signals sent by the 'troubled' family member. Quite a few people conceal to the utmost that they have discovered a symptom or an abnormal behaviour in their everyday activities.[36]

3.1. Forgetfulness or Dementia?

It is a platitude that every human being is unique and unrepeatable. Therefore, given diseases including the different types of dementia – besides the many general symptoms – appear in different forms. Furthermore, every type of dementia is characterised by a different course.

http://neurosurgery.pote.hu/idegseb/dat/isebjegyzethu/f4.html Downloaded on 20/07/2019

[35] https://nanocs.wordpress.com/2016/02/11/a-harom-majom-ne-lass-ne-hallj-ne-beszelj Downloaded on 25/07/2019

[36] Szokoli (2015)

Even an active and young person happens to forget something during everyday activities. At this age, it can be due to stress, overwork or the performance pressure. On stressful weekdays burdened by tight deadlines, one has no time to pay attention to tiny signs such as not remembering a familiar name. One does not realise for a while either, that he/she has to search for a daily use item – key, cheque or wallet – that has been put to the wrong place. For a long while, nobody will be alarmed by the fact that someone is huffy, sad or worried.

In most cases people affected by dementia and some of their relatives do not attach much importance to the problems or they just blame the workload, life situation, change or ageing, even if they realise that 'they should know that', or 'he/she does not behave like that'. It is important to know that patients with keen intellect are able to conceal the symptoms for a long time. Therefore, the family will have to face a spectacular deterioration in the patient's condition.

The many little things and the less spectacular signs should be a warning after a while, and the constellation of symptoms should be indicative.

When symptoms occur, it is worthwhile for the partner and family members to monitor the behaviour of the affected family member as well as his/her activities performed. It may be a warning sign that the fulfilment of the daily routine tasks becomes slower or even stalls sometimes, while later difficulties will occur in fulfilling complex tasks.

Changes in communication may also be good indicators. One of the first signs of communication problems is that the patient cannot speak fluently. He/she holds unnecessary breaks in the middle of the sentences and searches for the proper word. Sometimes meaningful sentences contain words that do not fit. Family members often mention that in these situations they did not intervene out of respect for the patient. Frequent 'loss' of different objects is the initial sign of temporal and spatial disorientation. The patient does not put the keys or the glasses to their places.

The early recognition of the symptoms and behavioural changes, the performance of the necessary medical examinations and the establishment of the diagnosis would all be vital. There are diseases in which the symptoms of dementia occur. Therefore, it is worthwhile to exclude or verify the presence of dementia via different examinations. In the current state of medicine,

diseases of dementia syndrome are incurable. However, the condition of the patient can be maintained at a certain level and the course of the disease can be slowed.

Early knowledge of the diagnosis is important because it provides an opportunity for conscious preparation for a period in which the ability to cooperate and think properlx becomes difficult or impossible.[37]

3.2. Help! Is it Possible that my Family Member is Suffering from Dementia? What shall I do now?

'The advantage of a bad memory is that one enjoys several times the same good things for the first time.' (Friedrich Nietzsche)

To put it in a nutshell the most important things are acceptance, support, love and to live the given day to the fullest. Living the moment calmly is also helped by environmental stability, living in the usual habitat, which can make a significant contribution to the patient's well-being. At the same time, it is important to prepare for the upcoming periods, to maintain and strengthen family relations and friendships in order to minimise isolation. The early recognition of the symptoms and the timely establishment of the diagnosis allows the family to brainstorm and then design the future.

Sincere communication is vital because the patient has the right to know what is wrong and what is going to happen. In the initial stage of the disease, there are no difficulties in communication therefore many future difficulties can be prevented. The quality of the communication is greatly determined by the quality of the parent-child or the spousal relationship, and the experiences and memories of the patient and his/her environment.

The quality of family relationships and the caring of the patient are greatly influenced by the different family structures and sizes. In traditional families, caregivers are mainly women (daughter, daughter-in-law). It is worthwhile to split caring tasks and to relieve the burdens of the caregivers from time to time.

[37] Szokoli (2015)

It is indispensable to contact healthcare providers (GP, psychiatrist, and neurologist) in order to establish a diagnosis as soon as possible. Different forms of social assistance should be mapped after or in parallel with the establishment of the diagnosis, even if the use of these services seems far away. Contacting social assistants and caregivers means support in solving the crisis and it may help the family in accepting an external expert to work with.

Nowadays more and more newspapers, books, and films deal with dementia and the change in the lives of individuals and families. Numerous websites can be found on this topic as well. It is useful to know the course of the disease so that advantage can be taken of all the opportunities to slow the disease. The conversion of nutrition, the enhancement of physical activity (e.g. regular walks) may set the process back. Finding a new hobby or playing with simpler memory games may also help. It is also important to know that the family should prepare for the upcoming periods even if the disease is stagnating.

Social relationships are vital in everyday life. Personal support, the maintenance and expansion of family relations, friendships and community relations are important for patients living with dementia as well. Communities and groups should be visited where the caregiver can get first-hand information based on personal experience. Such communities operate within the network of Alzheimer Cafés, which can be found in a growing number of municipalities, and the so-called fellow support groups, established and run by the affected people.

From being a relative to becoming a caregiver of a patient suffering from dementia will be a difficult process and a task that requires patience. The different types of dementia – depending on the stage – are mostly accompanied by behavioural and psychic changes. The everyday management of these changes may be challenging since the relatives are usually not prepared for them. All help is needed. The best what the relatives can do is that they collect information about the disease in order to know what to expect in the future. Thus, there is enough time available for psychological preparations.[38]

[38] Szokoli (2015)

4. PROVIDING CARE FOR A PATIENT WITH DEMENTIA

Family plays a huge role in the recognition of the disease in order to bring the patient to the doctor as soon as possible. Care is mostly provided by the female family members of the family (daughter-in-law, daughter, niece, grandchild). During caregiving the human dignity of the relative suffering from dementia has to be preserved and respected. If patient is provided with care by someone who is not a family member, a caregiver must be chosen who is accepted by the patient. A relationship of trust between the patient and the caregiver is indispensable for quality and personalised care.

The caregiver has to complete different caring tasks in the different stages of dementia. Initially the patient is self-sufficient while with the progression of the disease he/she will need 24-hour surveillance and care. Care can be provided at home or in an institution. During caregiving one has to strive to maintain the patient's skills, it is important to avoid overcare. It is necessary to find out what activities the patient with dementia can do on his/her own and let him/her to do those, even if he/she fulfills the given task slower (e.g. dressing up, putting up the shoes, doing the washing up, eating etc.). It is important that the caregiver should wait until the patient accomplishess a given task.

During daily care it is important to set up a daily routine which will help the caregiver and the patient as well in everyday life. In the moderate/severe stage the patient will not be able to fulfill the given task despite the instruction. Therefore, showing the specific activity may help the patient (e.g. using cutlery during eating).

In our lives, needs are rooted in deficiencies that require satisfaction. Needs can be grouped according to several criteria. The most well-known pyramid of needs was created by Abraham Maslow (1908–1970). According to his theory needs can be organised into groups and people have to satisfy their basic needs first, only after that will higher level needs arise. Maslow says that one of the basic needs is the physiological need which can be found at the lowermost level of the pyramid. Physiological needs include lower level needs such as nutrition, breathing, hygiene, clothing, rest, moving, etc. All these serve as a basis for higher level needs.[39]

[39] Jeszenszky, 2006 file:///C:/Users/Fito/Downloads/jeszenszky-zita---demens-idosek-ellatasanak-iranyelvei%20(2).pdf Downloaded on 20/07/2019

4.1. Nutrition and Meal

A healthy daily diet should include all food groups i.e. protein, fat (mainly vegetable oils e.g. sunflower oil, rapeseed oil, olive oil), carbohydrate, fibre and vitamins (C, folic acid, B1, B2, B6, B12). Protein intake can be provided by meat, eggs, dairy products, seeds and leguminous plants. Consuming fish is the easiest way to ensure the intake of Omega-3 polyunsaturated fatty acid which is indispensable for natural nutrition. For a fibre-rich diet the elderly person should consume whole wheat bread, fruit and vegetables on a daily basis. With ageing digestive problems may occur which often result in constipation. This can be avoided by having a fibre-rich diet mentioned above.

Fat intake is indispensable for the absorption of vitamins as well, but the consumption of too fatty food should be avoided because they burden the digestion of the elderly person and may lead to obesity. Physical activity declines with ageing therefore calorie requirement of the body decreases. A low-calorie daily diet is necessary for the elderly person preferably with five meals per day. The caregiver should provide balanced diet by taking into consideration the condition (e.g. dentition, food intolerance, taste) of the person with dementia (for instance if incomplete dentition occurs, pureeing of the meal is recommended). The following problems may arise during the nutrition of people with dementia:

- patient's appetite changes,
- patient does not feel hunger,
- decline in taste perception,
- patient forgets that he/she has already eaten,
- patient forgets the proper use of cutlery,
- due to hand tremor the patient is not able to use the cutlery appropriately,
- with the progression of the disease dysphagia may occur. Therefore, food must be chopped, or even pureed.

As with all care activities, the caregiver's patience is indispensable when providing the patient with food. In order to maintain the patient's self-esteem, the elderly person should be allowed to eat on his/her own until he/she is able to do so. Simple meals help the person living with dementia: it is useful to focus on the given activity therefore distorting factors that may divert the patient's attention should be excluded.

Only one type of food should be given to the patient at once. The food should be at an appropriate temperature: if it is cold, it will not be delicious, however if it is too hot, it may

burn the patient's mouth. Due to the decreased sense of taste, people with dementia may use too much salt. After the first flavouring, it is recommended to put the salt away.

While eating, the patient's attention may become unfocused. If that is the case, the patient should be advised gently to carry on eating. If communication is impaired and comprehension difficulties occur as well, the presentation or initiation of certain movements may help.

Difficulties in using the cutlery may occur in the moderate or severe stage of the disease. If the patient is not able to eat soup with a spoon due to hand tremors, it is recommended to put fluid food into a mug that is provided with a spouted lid and handles.

Figure 4: A mug that is provided with a spouted lid[40]

Figure 5: A mug that is provided with a spouted lid and handles[41]

With the progression of the disease, considerable difficulties in using the cutlery may occur. At this point, aesthetic eating is not a priority. In order to keep the environment clean, it is recommended to protect the table (e.g. with a waterproof cloth) from spilling food or drink. Instead of a fork and a knife, it is advisable for the patient to use a spoon with which he/she can eat independently. If possible, choose thick-handled cutlery, which is available in medical equipment shops.

[40] https://gyogyaszati.hu/search/page=1/?t_kereso=poh%C3%A1r Downloaded on 05/11/2019
[41] https://gyogyaszati.hu/search/page=1/?t_kereso=cs%C5%91r%C3%B6s+poh%C3%A1r Downloaded on 05/11/2019

Figure 6: Special spoon, right handed[42] **Figure 7:** Special fork, right handed[43]

It is recommended to puree bigger pieces of food. It is advisable to make toothsome bites that the person with dementia can easily eat with a spoon or with his/her hands. Dysphagia may occur in the severe stage of the disease. If that is the case, the elderly person should not be left alone while eating. Since dysphagia may lead to severe consequences (damage to the oesophagus, suffocation), it is important to take the necessary precautions. Food is advisable to be pureed, smoothies can be prepared from vitamin-rich fruits.

Besides eating, it is also important to talk about fluid consumption as well. A newborn baby is 70 percent water, while an elderly person is 50 percent. A person with dementia will consume less and less liquid. At the onset, the patient consciously drinks less in order to avoid unpleasantness related to urination or incontinence. With the progression of the disease, the decrease in fluid intake is unintended. The sense of thirst may be damaged, just like the sense of hunger.

Experience has shown that if a person with dementia is asked whether he/she is thirsty, the patient answers that he/she is ‘not thirsty’ or has ‘just drunk’. If he/she gets a glass of drink he/she puts it down after a few sips. The patient must be warned regularly about fluid intake. It is vital for the caregiver to control fluid intake because 2 percent fluid loss may lead to dehydration, which may damage health (confusion, unrest, kidney problems, etc.). The recommended daily fluid intake is between 1.5 and 2 litres. Consuming juicy fruits also boosts fluid intake (e.g. if dysphagia occurs freshly squeezed juice or smoothie is recommended).[44]

[42] https://gyogyaszati.hu/search/page=1/?t_kereso=U00014643/kanal-eletviteli-jobbos-medigor/716, Downloaded on 05/11/2019

[43] https://gyogyaszati.hu/termekek/rehabilitacios-es-gyogytorna-termekek/10/eletviteli-eszkozok-konyhai-etkezes-eszkozok/163/page=2/eletviteli-villa-jobbos-medigor/713 Downloaded on 05/11/2019

[44] https://www.tankonyvtar.hu/hu/tartalom/tamop425/0011_1A_Gerontologia_hu_book/ch01s03.html Downloaded on 16/07/2019

4.2. Hygiene, Bathing, Incontinence

The recognition and satisfaction of hygiene needs are vital. It can be an alerting symptom when the relative who has been neat so far becomes visibly neglected. He/she does not change his/her clothes or maybe seems slovenly. In this stage, intervention is indispensable. The occurrence of these symptoms means that the disease has reached a stage in which self-sufficiency has declined. Therefore, intervening is necessary in the patient's life. The patient needs to be reminded of the satisfaction of hygienic needs in a way that is neither hurting nor humiliating and at the same time respects the patient's human dignity.

With the establishment of the daily routine, the number of confrontations – stemming from the refusal of bathing – can be decreased. If the person with dementia did not have a bath on a daily basis before the appearance of the disease, daily bathing should not be forced.

The patient may refuse having shower or washing hair because he/she:

- feels ashamed to be nude,
- is unable to fulfil the task properly and a sense of failure develops,
- had an unpleasant experience during/after bathing or showering (e.g. the water was too cold or too hot, water splashed into the eyes, hairdryer's air was too hot),
- feels insecure (lack of grab bar, slipped previously),
- used an inappropriate personal care product (e.g. too intensive odour, eye-stinging shampoo). Therefore, the patient him/herself should choose these products during a joint shopping.

These problems can be solved if a family member who is accepted by the patient initiates the activity (e.g. son or grandchild instead of the daughter). If the patient is able to carry out some activities alone, he/she should be allowed to do so.

The bathroom should be heated up to a pleasant temperature (the patient should not be cold during bathing), water temperature should be adjusted to the patient before bathing. A grab bar and an anti-slip mat are indispensable in the bathtub or shower. Wash the patient's hair separately, for instance with the patient sitting on a chair and leaning over the washbasin. Avoid hair drying with too hot air.

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https://www.webbeteg.hu/cikkek/betegapolas/17943/megfelelo-etrend-idosek-szamara Downloaded on 16/07/2019

If incontinence occurs, special attention should be paid to proper hygiene, skincare and the avoidance of a sense of shame. The initial symptom is urine leakage then total incontinence develops after minor or major 'accidents'. At first, the symptom frightens the patient. A sense of shame develops and the patient tries to hide the traces of urine (puts paper or rag into the underwear).

It is hard to explain to people living with dementia why the use of aids like diapers or sanitary pads is so important. The use of sanitary pads may be enough against urine drops. When involuntary urination occurs, it is advisable to apply diaper panties instead of underwear. Since diaper panties are similar to normal underwear, patients with dementia accept them easier.[45]

4.3. Skincare

One of the physiological changes of the elderly is the alteration of skin structure and quality. With ageing the skin grows thin and becomes vulnerable. The most common symptom is dry and itchy skin, causing discomfort for the person with dementia. It is not sure that the patient is able to express his/her problem. Therefore, if the patient is fidgety and regularly scratches and/or rubs his/her forearms or legs but there is no sign of bites or rashes, then the skin is dehydrated. (Itching may occur due to inadequate toiletries as well.)

With the appearance of incontinence, special attention should be paid to skin protection. The skin surface should be washed with lukewarm water and wiped dry every day. Skin-protecting crème should be applied as well on a daily basis.[46]

Pedicure is essential in old age as well. An ingrown toenail may annoy the person with dementia because it may cause pain when walking. Therefore, the patient may refuse to go for a walk. Foot and nail care requires great attention. It is necessary to soak the patient's foot into lukewarm water and apply emollient creme every week to avoid cracked skin.

If proper nail care is problematic for the caregiver, a pedicurist is needed, who has the appropriate tools for precise nail clipping. In the severe stage of dementia, the patient may become bedridden which may cause bedsore. Bedsore means the appearance of skin redness

[45] Cayton–Graham–Warner,2006
[46] https://www.urologiaikozpont.hu/inkontinencia Downloaded on 12/07/2019

first, then deepening wounds on those parts of the body which are exposed to pressure (sacrum, heel, buttock, knees, tailbone, scapula, back, aitchbone, ear, sometimes scalp).

Great emphasis should be laid on prevention! It is important to turn the patient over in the bed regularly. If the patient is able to turn over in the bed on his/her own, it is recommended to remind him/her in every 2 hours to change position. If the patient is unable to turn over on his/her own, the caregiver should do that. Propping the patient after turning him/her over may help.

In order to prevent bedsore, it is indispensable to provide proper hygienic conditions and skincare. Bloodstream can be improved and tissue necrosis can be reduced with regular massage of the pressured areas. It is advisable to rub the skin with alcoholic solution (e.g. rubbing alcohol) or with a skin regenerating gel, which prevents bedsore.[47]

The following medical aids can be used if needed:
Heel cushion and elbow cushion:
The development of bedsore can be avoided with the use of medical aids since they reduce pain and provide comfort. The 'Gyopár' cushion (filled with foam balls) allows the patient to be fixed in one posture.

Figure 8: Heel cushion/elbow cushion[48]

[47] https://www.felejtek.hu/gondoskodas.html?gclid=CjwKCAjw8ZHsBRA6EiwA7hw_sWTld-Y4HUs3gxW0l0dg95VlSClFqrJlJMnMEuuot5m8Slu_g2A6QBoC02YQAvD_BwE Downloaded on 12/07/2019
[48]https://gyogyaszati.hu/search/page=1/?t_kereso=Sarokgy%C5%B1r%C5%B1+%2F+k%C3%B6ny%C3%B6kgy%C5%B1r%C5%B1+t%C3%A1mp%C3%A1rna+S8+gyop%C3%A1r+k%C3%B3d%3A+U00001311 Downloaded on 05/11/2019

If possible it is worth using an anti-bedsore mattress that helps in preventing the development of bedsore. The most well-known types of anti-bedsore mattress are the custom-designed foam mattress (e.g. egg crate foam) and the electronic anti-bedsore mattress which improves bloodstream by exerting variable pressure on the patient's body.

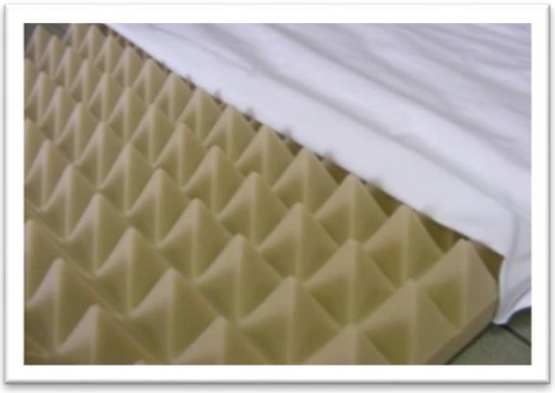

Figure 9: 'Perimed' anti-bedsore mattress[49]

Figure 10: Electronic anti-bedsore mattress[50]

4.4. Dressing Up

In the initial stage of dementia, neither the selection of seasonal clothing nor dressing up is problematic. With the progression of the disease, it may be an alarming symptom that the person with dementia does not wear seasonal clothes (e.g. wears a sweater in the summer or flip-flops in the winter), or the patient puts on his/her clothes in the wrong order (e.g. wears an undershirt over the T-shirt or an underwear over the stockings).

Keeping only seasonal clothes in the wardrobe helps the patient in choosing the appropriate pieces. It is recommended on the one hand to keep the clothes in the wardrobe folded and grouped, on the other hand to label or put pictograms on the shelves (e.g. 'underwear', 'T-shirts', 'sweaters', etc.).

It is important to adjust the clothes to the patient's size, following the changes of his/her body shape (e.g. losing or gaining weight). The patients have difficulties in handling the buttons from

[49] https://gyogyaszati.hu/search/page=1/?t_kereso=decubitus%20/perimed-antidecubitus-matrac-932-tipusu-70-kg-felett/1292 Downloaded on 05/11/2019

[50]https://gyogyaszati.hu/search/page=1/?t_kereso=%20Elektromos%20antidecubitus/felfekv%C3%A9s%20elleni%20matrac%20II-IV%20st%C3%A1dium%20kezel%C3%A9s%C3%A9re%20k%C3%B3d%20U00007024/elektromos-antidecubitusfelfekves-elleni-matrac-ii-iv-stadium-kezelesere/2626 Downloaded on 05/11/2019

the moderate stage of the disease due to the decline in fine motor skills and to the possible hand tremors. It is practical to purchase clothes that the patient can put on independently (e.g. clothes with loose sleeves, zippers instead of ones with buttons). Thus, the sense of failure is avoidable.

With the progression of the disease, the patient may become unable to choose the proper clothes. Therefore, the caregiver shoud do that and help the patient in dressing up by making requests. The patient should be dressed up in the severe stage of the disease. A frequent problem is that the person with dementia does not want to change clothes because insists on what he/she is wearing. In this case, it is practical to buy more of the given item at once, thus the clothes become washable and changeable.

With dementia becoming more severe, caring tasks will be changed as well. It should be recognised, how and when the patient should be provided with help. The patient should be provided with just as much help as he/she needs in the given condition.[51]

4.5. Appropriate Physical Activity

During caring, the opportunity to do appropriate physical activity (e.g. regular walking, seniors' dance based on simple choreography, chair exercises – 'Béres' Chair Exercises for instance, etc.) should be provided for the person with dementia. Regular physical activity is worth being included in the daily routine. Physical activity is indispensable for normal muscle functions, digestion, immune system, while it may also influence blood pressure, the level of blood lipids, prevent obesity and eliminate sleep disorders etc.

When choosing the form of physical activity the highest priority is personal safety. Balance problems occur quite soon in old age, particularly within the syndrome of dementia. Sudden movements should be avoided during physical activity. The form of physical activity should always be chosen in accordance with the abilities of the patient. The patient should be provided with comfortable clothing for physical activity.[52]

[51] http://foh.unideb.hu/sites/default/files/upload_documents/magyar_gerontologia_2.7.pdf Downloaded on 13/07/2019

[52] Jeszenszky,2006. file:///C:/Users/Fito/Downloads/jeszenszky-zita---demens-idosek-ellatasanak-iranyelvei%20(4).pdf Downloaded on 13/07/2019

4.6. Sleeping

Caregivers often report that the patient with dementia suffers from sleep disorder. Sometimes the patient interchanges the parts of the day (sleeps during the day, walks at night). With the progression of dementia, a new habit may appear: the patient repeatedly takes the clothes out from the wardrobe then puts them back during the night. This places a huge burden on the caregiver. Experience shows that if people with dementia do regular physical and daytime activities (e.g. housework, word games, etc.) they are less likely to suffer from sleep disorders. The reason for restlessness is worth revealing. In the severe stage of the disease, the patient is hardly able to express him/herself, if at all. Therefore, the patient's night-time restlessness may stem from pain, unpleasant feeling or unsatisfied need (e.g. hunger, thirst, urination/defecation stimulus). If sleep disorder is persistent or returns regularly, medication treatment is necessary in order to protect the patient and the caregiver as well.[53]

4.7. Communication with a Person with Dementia

Information is exchanged during communication, which may happen verbally or non-verbally (facial expression, posture, gesture, mimicry). Communication skills of people living with dementia decline gradually with the progression of the disease. Initially the patient has fluttering thoughts, he/she loses focus in conversations, sometimes suffers from word-finding difficulties. If deterioration in sight or hearing occurs, it is necessary to purchase a pair of glasses or hearing aid.

With the progression of the disease, communication difficulties exert an increasing impact on the life of the person with dementia. The patient finds expressing his/herself more difficult, and he/she is unable to participate in longer conversations. Due to the failures, the patient speaks less which may lead to isolation and loneliness. The most important is that the caregiver should show patience.

If the patient has self-expression difficulties, he/she should be given enough time to try to tell what he/she wants. Urging may generate negative feelings and make self-expression even more difficult, which may lead to a sense of failure and anxiety.

[53] file:///C:/Users/Fito/Downloads/jeszenszky-zita---demens-idosek-ellatasanak-iranyelvei%20(4).pdf
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Proper communication has a key importance in some caring activities. It is always advisable to speak simply and openly, in short sentences. Requests should be understandable and easy to execute. Shouting and huffy communication should be completely avoided even if the caregiver is running out of patience after the umpteenth repetition. Relaxed speaking style is always more efficient, while tense and annoyed communication may trigger aggression from the patient.

Keeping eye contact as long as possible during a conversation is essential. It is easier when the heads and shoulders of those who participate in the conversation are in the same height. Drawing and maintaining the attention of the patient may be difficult, but holding his/her hand gently may help. Some people with dementia find it harder to accept physical contact, but in most cases (e.g. when the patient is restless) touching, caressing, holding hands may be useful.

Relaxed and open communication makes it easier to attract and maintain the patient's attention. It is important to know that when verbal communication is hampered, attention has to be paid to body language, which may be a good indicator of the current condition or mood. The exclusion of external factors (e.g. television, radio) during the given activities may foster the maintenance of the patient's attention.[54]

4.8. Medication

Only a specialist (neurologist, psychiatrist) is entitled to initiate pharmacotherapy that is adjusted to the type of dementia and the severity of the symptoms. The caregiver plays an important role in the correct dosage adjustment because he/she is able to provide the specialist with the most accurate description of the patient's daily routine and habits. Therefore, the caregiver should escort the patient to the doctor.

Dementia is incurable. As time goes by continuous deterioration can be expected. Drugs prescribed by the specialist are only able to improve the quality of life and the clinical condition. They cannot cure the disease itself, but they can slow down the course of the disease.

Presence at the regular medical examination is vital in order to adjust medication to the changes in the condition of the patient. It is necessary to keep in touch with the GP and the specialist.

[54] http://www.mek.oszk.hu/02000/02009/02009.htm Downloaded on 13/07/2019
https://www.tankonyvtar.hu/hu/tartalom/tamop425/0005_03_a_kommelmelet_alapjai_scorm_02/32_a_kommunikci_fogalma.html Downloaded on 13/07/2019

In the initial stage, the fear of the disease, while later with the progression of the disease the lack of disease awareness, agitated behaviour, walking difficulties or bedridden status may make it harder or even impossible for the patient to turn up at medical consultations. If the patient is unable to appear at the consultation due to one of the reasons listed above, it is advisable for the caregiver or a relative to meet the doctor in order to inform him/her about the changes in the condition of the patient. It may happen that it takes longer to adjust the medication to the patient and the firstly prescribed does not work. Thus, it is important to inform the specialist immediately about the situation.

It is the caregiver's responsibility to ask the specialist for the prescriptions, to purchase the medicine and to check whether the patient has taken them because it is vital to take the pills at the proper time (there are medicines that should be taken in designated times of the day). The patient's memory – particularly the short term – is continuously deteriorating. Due to the forgetfulness, it is not safe anymore to let the patient take his/her medicine alone. The patient may forget to take the necessary dose or it is even worse when he/she forgets that he/she has already taken it and takes one or – in the worst case – even more doses.[55]

4.9. Taking Care of the Caregiver

At the beginning of this chapter, it has already been mentioned that the caregiver is typically a family member who is responsible for the full care of the patient. The caregiver is a part of the everyday life of the person with dementia. Therefore, the caregiver is the first who faces the behaviour or possibly the emotional swings of the patient, the changes in the patient's condition, and the conflicts. Psychic changes may be very diverse: it happens that the patient's behaviour changes in a very short time, i.e. in some minutes or a few hours. The caregiver should try to perform the caring tasks to the best of his/her knowledge and abilities. For that, it is indispensable to broaden the knowledge of dementia, to have the support of the family, or maybe to be able to rely on external resources. On the one hand, the caregiver feels him/herself competent due to the knowledge he/she gathered about the disease, on the other hand, he/she understands the behaviour of the patient better, becomes able to handle changes more flexibly, and the relationship between him/her and the patient may become more accepting, safer and smoother.

[55] http://aek.gov.hu/rovatok/kozpontrol/kozpontrol/alapdokumentumok/mees/download/mees.pdf
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Care is a long process that may last for even decades, during which it is advantageous and ideal to share the burdens among the family members, based on their capacities. If the caregiver carries the burdens alone, he/she gets tired or exhausted earlier. He/she needs recreation, which means serious logistical (organising) tasks. It is highly important to maintain the health and mental condition of the caregiver, since the negative changes in his/her condition will affect the patient's condition as well.

During taking care of the patient, the caregiver is on an emotional roller coaster. The caregiver experiences less positive, but more negative feelings during the caregiving (e.g. inertness, wrath, fury, shame, impatience, anxiety, concern, doubt, qualm, aggression, refusal, crankiness, arrogance, heatedness, indiscretion, condescension, stress, self-loathing, selfishness, apathy, resentment, disrespect, retreat, lack of loyalty, dispraise, scapegoating, collapse, agony, paralysis, contempt, unbelief, death wish, fear of death, dread). It is difficult and stressful for the caregiver to handle and to experience these feelings.

The caregiving family member does not dare to admit, accept, or express his/her feelings for him/herself, as he/she is not always able to identify whether or not the feeling he/she is feeling is appropriate. Is he/she free to talk about these feelings or not, and if so, to whom? Is there anyone at all, who understands him/her?

It is important for individuals to recognise, articulate and not to feel ashamed of their feelings. If the individual becomes more open and freer, will show more willingness to talk about him/herself,

If individuals learn how to speak out their deeply concealed (negative) feelings, that results in relief, through which anyone becomes more open and freer and shows more willingness to talk about emotional states. .

The so-called Group of Relatives is one of the supportive communities where a safe atmosphere is created for emotional support. External support (e.g. family member, friend, neighbour, social

provider, churches) should be involved in order to provide the caregiver the opportunity to do free-time activities and to maintain his/her social relationships.[56]

4.10. Special Care

'As long as we have the capability let's place our shoulders under the other man's cross under which he is on the verge of collapse!'

(Endre Gyökössy)

In the severe stage of the disease, the patient may need institutional placement because of the continuously deteriorating condition. The most important question when making a decision is whether the caregiver is still able to take care of the patient safely at home. It is advisable to prepare this step right after the establishment of the diagnosis.

Special care is justified when:

- the patient lives alone, strays regularly,
- behavioural disorders cannot be treated,
- the person with dementia is a danger to self and others,
- the patient becomes bedridden and the family is unable to take care of him/her at home,
- the patient does not consume the amount of protein, fat, carbohydrates, vitamins and calories which are needed for the maintenance of life, therefore artificial nutrition (parenteral nutrition) is necessary, which bypasses the digestive system.
- fluid intake is hampered, therefore infusion is continuously needed,
- severe bedsore, ulcerative wounds occur.[57]

[56] Professional protocol of the Ministry of Health: Diagnosis, Treatment and Care of Dementia; Prepared by Professional Collegium of Psychiatry;
Papp,K–Újváriné,Siket A.(2014.)
Cayton–Graham–Warner:,2006.
Juhász,2018.

[57]https://inda.info.hu/uploads/dokumentumok/interprofesszion%c3%a1lis_demens_ell%c3%a1t%c3%a1s%20alternat%c3%adv%c3%a1i.pdf Downloaded on 25/06/2019

5. CHANGES IN EVERYDAY LIFE

Maslow's hierarchy of needs has already been mentioned in the second chapter. According to the famous pychologist, basic physiological needs – in a bottom-up approach – are followed by safety needs. During the care of the patient living with dementia, special attention has to be paid to the safety of the living environment and of the patient as well.

When the patient or his/her relative faces the diagnosis of dementia, the planning of the future should be started. The disease is irreversible, during its long course the individual and his/her social environment face different difficulties in every stage of the disease. Information and knowledge on the disease definitely help in the adequate management of the significant changes and problems emerging in everyday life. The patient suffering from dementia has difficulties in coping with deviations from the usual. Therefore, if the family chooses home care they have to make the living environment safe. By taking the attributes of the dwelling into consideration, spaces should be formed where the person with dementia can live an independent life.

5.1. Making the Dwelling Safe

A safe environment makes the patient's and caregiver's life easier as well. In the initial stage of the disease, the patient and the caregiver can make the necessary decisions together thus the dwelling will be comfortable in a later and more severe stage of the disease as well. The interior should not be overcrowded. Rooms should be transparent with easily understandable functions. The elimination of overcrowding can easily be a source of conflict since objects represent memories. Therefore, the ageing person is not willing to get rid of them. In a certain stage of the disease, the patient may start collecting a huge amount of unnecessary objects.

It is worthwhile to label (or place pictograms in) the different rooms to prevent the person with dementia from getting lost in the dwelling (e.g. the patient goes into the bathroom instead of the toilet and by the time he/she finds the proper room it is too late). In the course of the disease spatial and temporal disorientation deteriorates therefore it is advisable to place large calendars and clocks in the different rooms of the dwelling.[58]

[58] https://inda.info.hu/uploads/dokumentumok/gondozasi_kornyezet.pdf Downloaded on 18/07/2019

5.1.1. Living Room

With the progression of the disease motor coordination disorder occurs, gait deteriorates and shuffling occurs. Therefore, carpets, rugs, cables and thresholds should be removed because they may increase the risk of falling and accidents. The floor covering must be non-slip and easy to clean. Seat height and overall comfortability should be taken into consideration when choosing furniture. The furniture should be easy to clean therefore it is worthwhile to provide the couch, the armchair, the chairs with washable cover.

Smaller cabinets, flower stands or other smaller furniture should not be placed next to the couch, chairs or armchairs because the patient may cling on to and upset them. In order to avoid accidents wardrobes should always be fixed to the wall. It is worthwhile to place the television in the living room.

The walls, curtains and other furnishings should be of calming, pleasant and harmonic colours. Big, vivid and disturbing patterns should be avoided when choosing home textiles. If possible, it is advisable to place photos of lovely memories for the person living with dementia onto the table, shelves and walls.

The living room should have a good lighting during the day, with shutters and blinds opened. If the patient usually leaves the bedroom at night (because of wandering or urination), motion sensor lights should be installed in order to avoid accidents.

5.1.2. Kitchen

Memory deteriorates with the progression of dementia thus the patient may forget the food on the cooker. This is particularly dangerous because it may catch fire. It is indispensable to make some decisions or even to introduce certain restrictions for the safety of the patient and his/her environment. It is worthwhile to provide the patient with hot food once per day after the first problems.

Cooking appliances (e.g. gas cooker, electric cooker) should be turned off in order to avoid accidents. It is worth installing a thermostatic mixer tap with colour indicators (e.g. blue: cold; red: warm) in order to avoid burns. The expiration date of the food in the fridge should be checked regularly. It is advisable to place a magnetic lock on the door of the fridge for better closure.

The attention of the person with dementia can be easily diverted at any time. It is dangerous if the patient puts the plug into the sink, opens the tap and in the meantime begins to focus on something else. With the sink plugged in, the water will flood the dwelling. Therefore, the plug should be kept out of the reach of the patient.

On upper floors, windows also pose threat. Remove everything from the vicinity of the window on which the patient is able to stand (e.g. chair). It is advisable either to remove the window handle or to modify the windows in a way that they can only be tilted.
Electronic devices (e.g. microwave oven) are worth turning off in the severe stage of the disease because the person with dementia may forget how to use them properly. Thus, these devices are potential sources of danger (e.g. the patient may put textile or metal into the microwave oven). These restrictions may seem to be drastic but they are indispensable to avoid accidents. It is harder to solve a problem than to take precautionary measures.

5.1.3. Bedroom

It is important to choose a comfortable bed and mattress. The floor covering should be the same as in the living room (non-slip, easy to clean, undamaged). Do not put a carpet/rug in front of the bed! It is worth installing a motion sensor light in the room. Light switches are easier to see if they glow in the dark. The tone of the lights should be warm. In order to ensure the perfect rest there should not be a television in the room. If the patient falls asleep while watching the TV, a louder sound effect may frighten him/her. The best solution is to use sliding doors because it can be opened even when the patient falls in front of it. Keys should be removed from the doors and should be kept out of reach of the patient. Thus, it can be avoided that the patient locks him/herself into the room.

5.1.4. Bathroom

Detergents kept in the bathroom should be locked up! Always keep only one kind of toiletries (e.g. shower gel, soap) within the reach of the patient because otherwise, he/she may get confused. With the progression of the disease, the patient will not always know what to use and when (e.g. he/she uses body lotion instead of shower gel). It is useful to purchase compact size toiletries because the patient can use them easier.

It is also worth providing the bathroom with a keyless sliding door. It is also recommended to remove the threshold in order to make the room barrier-free. The floor should be covered with

a non-slip surface and a non-slip mat is necessary in front of and inside the shower. Initially, a bathtub is also adequate, but with the progression of the disease, difficulties occur in getting in and out of the bathtub. Remodelling the bathroom may help but if it is impossible due to financial or other reasons, making the bathtub barrier-free may also be a good solution.

In this case, a door is cut in the side of the bathtub through which the patient is able to get in and out of it:

Figure 12: Barrier-free bathtub[59]

Another way to make the bathroom barrier-free is to install a tub shower.

Figure 13: Tub shower[60]

[59] https://furdokadajto.com/portfolio-item/akrilkad_kadajto Downloaded on 18/07/2019
[60] https://www.zuhanykad.hu Downloaded on 18/07/2019

It is advisable to install grab bars onto the wall in order to enhance the safety of the patient. There are many types of wall-mounted grab bars available in the market.

Figure 14: Straight grab bar[61]

Figure 15: Two-part grab bar[62]

It is also recommended to purchase medical aids in order to make bathing easier.

Figure 16: Bathtub seat[63]

Figure 17: Adjustable shower seat[64]

Figure 18: Wall mounted shower seat[65]

[61] https://gyogyaszati.hu/search/page=1/?t_kereso=%20-%20B%204303%20EGYENES%20KAPASZKOD%C3%93%20k%C3%B3d%20B4303/b-4303-egyenes-kapaszkodo/672 Downloaded on 18/07/2019

[62] https://gyogyaszati.hu/search/page=2/?t_kereso=kapaszkod%C3%B3/furdoszoba-kapaszkodo-vp-ketreszes/7505 Downloaded on 18/07/2019

[63]https://gyogyaszati.hu/search/page=1/?t_kereso=f%C3%BCrd%C5%91k%C3%A1d%20%C3%BCl%C5%91ke/furdokad-uloke-fix-b-4320/638 Downloaded on 05/11/2019

[64] https://gyogyaszati.hu/search/page=1/?t_kereso=f%C3%BCrdet%C5%91sz%C3%A9k/tusoloszekfurdetoszek-allithato-magassagu-m-bl/3019 Downloaded on 05/11/2019

[65] https://gyogyaszati.hu/search/page=1/?t_kereso=tusol%C3%B3%20%C3%BCl%C5%91ke/b-4311-falra-szerelheto-tusolouloke-felhajthato/637 Downloaded on 05/11/2019

Similarly to other rooms, it is again recommended to remove the key from the door, thus the patient cannot lock himself/herself into the bathroom. Similarly to the kitchen, it is worth installing a thermostatic mixer tap with colour indicators (e.g. blue: cold; red: warm).

Grab bars should be mounted onto the wall of the restroom. Furthermore, a raised toilet seat should be mounted on the toilet firmly (e.g. it should not slip on the surface). The colour of the floor cover is recommended to differ from the colour of the toilet bowl. The toilet seat should be put down and the cover should be opened because it is not sure that the patient is able to assess the situation and he/she will use the toilet as he/she has found it (e.g. sits on the toilet bowl or on the cover). It may happen that the patient will be unwilling to use the restroom due to the unpleasant experience, and he/she will retain urine.

The raised toilet seat helps the person with dementia in sitting down, getting up and sitting over from the wheelchair.

Figure 19: Raised toilet seat[66]

Figure 20: Raised toilet seat with removable arms[67]

5.1.5. Yard/Garden

The highest priority is safety. Therefore, it is necessary to install handrails on both sides of the stairs that the person suffering from dementia can lean on. The stairs should also be provided with non-slipping material.

[66] https://gyogyaszati.hu/search/page=1/?t_kereso=wc%20magas%C3%ADt%C3%B3/meyra-easy-clip-wc-magasito-fedellel-15-cm/7720, Downloaded on 05/11/2019
[67] https://gyogyaszati.hu/search/page=1/?t_kereso=wc%20magas%C3%ADt%C3%B3/wc-magasito-kiveheto-karfaval/2469, Downloaded on 05/11/2019

The yard should be barrier-free and well lit. If possible, it should have a place where the person with dementia can go for a walk. Relaxation areas within proper distances should be provided in the garden/yard where the patient can rest on a bench or chair of appropriate seat height during his/her walk. It is not recommended to have poisonous plants in the garden and the existing ones should be removed as well.[68]

Figure 21: Small, interesting and safe: Alzheimer garden[69]

5.2. Developing a Sense of Personal Safety

It has already been mentioned that the caregiver is the most important person in the patient's life. Patient safety also means the establishment of a harmonious relationship of trust between the patient and the caregiver. It should also be valid when not a family member, but a friend or a paid professional is entrusted with the task. The person with dementia is completely vulnerable to the caregiver therefore a relative should in all circumstances monitor the relationship of the patient and the caregiver. In order to satisfy safety needs, it is necessary to make the environment safe and to ensure the personal sense of securityty.

[68] https://www.betterhealth.vic.gov.au/health/ConditionsAndTreatments/dementia-safety-issues, Downloaded on 20/08/2019
https://www.alz.org/help- support/caregiving/safety/home-safety Downloaded on 20/08/2019
[69] https://www.flowerpotman.com/gardening-for-the-elderly-and-disabled/design-for-alzheimer-s-garden/ Downloaded on 20/08/2019

Initially, the patient is able to live independently, but with the deterioration in his /her condition, the signs of poor judgement occur. In this stage, a 24-hour-monitoring is necessary for the patient's own safety. With the progression of the disease, the patient is not always able to express him/herself. Thus, he/she may become huffy and tense because of certain unsatisfied needs. A safe dwelling is a huge contribution to personal safety since grab bars, proper lights, pictograms, the water of adequate temperature, etc. all add to the personal sense of safety.

With the early recognition of the disease, the patient can entrust a person to act on behalf of him/her when he/she will be unable to make responsible decisions. It happens that the patient should be restricted for the sake of his/her own and his/her environment's safety. People with dementia often become the victims of swindlers, who deceive the elderly and take their money. Without restrictions, the person with dementia may even transfer his/her real estate to swindlers. In the moderate stage of the disease, patients hardly, if at all, know the value of money. Therefore, they need assistance in managing their finances. The patient's financial security can be ensured if the patient has access to only a certain part of his/her income.

The caregiver has a hard time when the person suffering from dementia wanders away. There are many devices to choose from that can help in this case. A safety lock on the door may prevent the patient from going out. If the patient has already left the dwelling, smart bracelets and smartphones with GPS tracking may help in finding him/her.

The Trackimo GPS tracker is an internet-based service. The exact location of the device can be checked on the website or via the application. The device alarms when the person with dementia left the designated area. The tracker is also equipped with an SOS button and a long-lasting battery. The device is waterproof. Tweezer and neck strap is also available (not included).

Figure 22: Trackimo GPS tracker[70]

[70] https://store.trackimo.com/products/3g-trackimo-gps-tracker Downloaded on 10/10/2019

It is advisable to provide the person suffering from dementia with a bracelet with the phone number of the contact person on it. If a person with dementia gets lost, it should be reported to the police as soon as possible and the search should start immediately. He/she may visit places that can be important for him/her (e.g. previous workplace, dwelling, parents' house, etc.). It is worth turning up at nearby service providers with the person with dementia (e.g. shop, restaurant, confectionery, etc.) thus if he/she turns up at these places alone, the staff can notify the caregiver.

Using the same routes every day may help the person with dementia suffering from deteriorated orientation. People with dementia after the occurrence of the symptoms should refrain from driving a car for their own and people's safety. Poor judgement, spatial disorientation, increased reaction time, forgetfulness etc. make driving unsafe. Patients sometimes do not accept easily that they are not able to drive anymore. The family should keep the car keys out of the reach of the patient. In order to reduce the urge to drive, it is advisable to take the car away from the patient's environment.[71]

5.3. Strict Daily Routine

In the initial stage of dementia, the patient is able to live independently, plan and fulfill the daily tasks (dressing up, washing the face, brushing the teeth, eating, shopping, free-time activities, resting, administration, etc.) independently. With the progression of the disease, memory disorders worsen, judgment becomes poorer and behavioural disorders may occur. As a result, even the fulfillment of routine tasks becomes difficult for the patient. When symptoms occur, it may be helpful if the patient or his/her caregiver makes reminders such as 'Close the…!', 'Put away…!', 'Take out…!', 'Switch off…!'.

For the people suffering from the disease, it is very difficult to adjust to changes and they do not easily deviate from the ordinary. Therefore, it is better to provide the patient with care at his/her home, but ONLY IF it is safe. Planning the day in advance helps most of the people. This is particularly important for the patient suffering from dementia because by establishing a daily routine, he/she can prolong his/her independence and live his/her life with dignity. When the disease gets more severe, the planning of and helping in the performing routine tasks will be the caregiver's burden. During accomplishing the daily tasks, it is important to avoid overcaring.

[71] https://www.alz.org/help-support/caregiving/safety/ Downloaded on 01/08/2019

If the patient is unable to carry out a series of tasks independently, the caregiver should not take over doing these tasks, but rather try to help the patient instead. Task fulfillment may be hampered by many factors. In such cases the root cause should be eliminated.

If the patient's **attention** is **diverted,** it is the caregiver's task to 'bring the patient back'. This means that the patient's attention should be directed but not in a rude or violent manner. The patient should be asked to carry on with the task. Tone and body language should suggest encouragement. Tense and huffy behaviour may induce stress in the patient, which may result in anxiety or complete refusal when it comes to doing the given activity.

If the patient suffers from **memory disorders**, he/she cannot remember how to perform a given task. With respecting human dignity, the patient should be guided through the activity with brief instructions. Instructions should always be short, clear, firm and should refer (only!) to the next step. In certain stages of the disease, comprehension disorders may occur, thus verbal instructions will not help. In this case, the activity should be done jointly to let the patient copy the task, or it has to be shown him/her what he/she has to do.

When the fulfillment of the task encounters an obstacle (e.g. the patient partially or completely unable to move his/her arm/leg due to a co-morbidity), the patient should be guided through that certain part of the given activity without providing him/her with excessive help. The patient should not be urged while performing the task. As a result, he/she gets positive feelings and a sense of achievement.

The preservation of independence is very important. If the patient is deprived of his/her independence prematurely, he/she will not do the task later, even if he/she is able to it. The establishment of the daily routine helps in planning the day, but it should be treated flexibly. Besides respecting the main points (meal, medication, hygiene, rest), the planned free-time activities can be modified or overwritten.

Leisure activities should always be adapted to the patient's current state, behaviour and mental mood. For instance, when a patient is stressful or nervous on a given day, it is not advisable to perform loud activities in a crowd, as this may further aggravate his/her psychic situation. Instead, it is advisable to choose home activities, such as reading, watching photos, or a beloved

film (not action or war film), listening to relaxing music or taking a long walk in the neighbourhood.

When planning the daily routine it should be kept in mind that with the progression of the disease, concentration skill deteriorates. Therefore, it is worth planning short free-time activities, while a short break after lunch is a good opportunity for the caregiver to have a rest.[72]

5.4. Maintaining and Expanding Relationships

People living with dementia ignore the first symptoms but later when forgetfulness causes problems (e.g. he/she has forgotten important things), or they find objects at different places (e.g. eyeglasses in the fridge, key in the wardrobe) they get scared.

The new situation makes the patient feel ashamed, even if he/she is able to compensate in the early stage of the disease (e.g. uses synonyms, or circumscribes a word when he/she has word-finding difficulties).

With the progression of the disease, the patient will not be able to compensate, his/her memory and self-expressing ability further deteriorate and all these lead to the development of the sense of shame. The patient begins to break off relationships to avoid unpleasant situations in front of his/her friends. Thus, the patient becomes isolated from the environment. This particularly characterises people who live alone.

The most important aspirations of professionals dealing with dementia are to change the attitude of the society and to achieve that patients and their close social environment (e.g. spouse, family and friends) do not experience the disease as a stigma and that neither the people with dementia nor their environment feel ashamed.

Information and knowledge on the disease my help a lot to the patient and his/her environment in dealing with certain problematic situations, which is caused by the beloved person's memory disorder, behaviour and deterioration of his/her skills.

With the occurrence of dementia, family relations change when the patient needs gradually more care. The wife and the children find themselves taking on the role of the caregiver as well. Dividing the roles is very difficult and the family members' activities are rather dominated by emotions, while with an outsider caregiver it is not the case.[73]

[72] https://www.alz.org/help-support/caregiving/daily-care/daily-care-plan Downloaded on 01/08/2019
[73] https://www.alzheimers.org.uk/get-support/daily-living/your-relationships Downloaded on 01/08/2019

6. THE ‘PERSON WITH DEMENTIA IS PROBLEMATIC’

‘Everything has an order. By the time one gets deeply sunk in a situation, a lot of time passes and we are getting used to the change.’ (Sándor Márai)

First, the notion of ‘problem’ and the meaning of ‘problematic’ person with dementia should be defined. Simply put, a problem is a task to solve. According to practitionerss of the social sphere, problems are made of those questions, situations and tasks that cause internal tension to the individual, the family or the group. Own resources, solutions or immediate answersare limited to solve the situation or to relieve tension. The treatment of the problem in the helping process requires motivation, participation, activeness and specific activities.

It is important emphasizing that the problem is not the person living with dementia, but the multitude of situations that surround this disease, and the lack of experience in solving these situations leads to the accumulation of problems. According to Szilveszter Horváth, ‘at a certain point of Alzheimer’s disease, everything turns into a problem’.

At the appearance of dementia, during the care of a relative living with dementia plenty of unforeseen, therefore not plannable situations and problems occur that have to be dealt with and solved. The solution may be considerably hampered by the fact that every case is different and it often happens that the family or the caregiver has no strategy to address the problem. Unique life situations, unique life stories and unique opportunities generate unique problems that require unique solutions and also the ‘problematic person with dementia’ will generate different tasks for the caring family or professionals.

Regarding dementia, the primary problem is the acceptance of the disease. Health is a value, and great emphasis is laid on healthy lifestyle as a part of everyday life. Regarding most chronic diseases, good quality of life is guaranteed even in the long term by proper therapy, lifestyle, and adherence to medical instructions. But with dementia this good quality of life is temporary, the course of the disease can be slowed down, but according to present knowledge the disease is incurable. Subsequent to the establishment of the diagnosis, the patient’s reactions and the handling of these reactions may pose a problem.

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https://www.nhs.uk/conditions/dementia/relationships-and-dementia/ Downloaded on 01/08/2019

Besides the lack of self-acceptance, the attitude of the immediate and extended family, the acceptance of the disease is a significant source of problems, but the attitude of the environment and the society is also decisive.

The insufficient knowledge, ignorance, insensibility, indifference, rejection, turning aside, or exclusion by the members of the family, the community and ultimately the society may also pose a problem. As a result, the affected patient and the caregiver along with the immediate family members (may) hide away, feel ashamed, and lead a secluded life. . The social attitudes and stereotypes of certain members of the society towards this demographic group further complicates this situation and hampers the acceptance of the elderly and elderly patients. It makes quite a difference whether the group of the elderly (which is heterogeneous) is regarded as a resource or as a burden.[74]

6.1. Social Attitudes towards Patients Living with Dementia and Their Families

In sociology, attitudes are generally psychic processes (interpreted in the social context) that determine the behaviour of individuals within the society.[75] G. W. Allport's definition of attitude from a social psychological perspective is as follows[76]: 'Attitude is a mental and neural state of readiness, organized through experience, exerting a directive or dynamic influence upon the individual's response to all objects and situations with which it is related'.[77]

A society is greatly defined by its attitudes towards the members of the society. There are significant changes in the field of ageing, which appear in the topic of active ageing. The activeness of the elderly may support the view that the silver generation should be treated as a resource while the period of ageing as an opportunity.[78] This approach appears also in a resolution of the Hungarian Parliament.[79]

The extent to what the provision of equal opportunities for the disadvantaged are fostered also shows a given society's tolerance (patience), solidarity (mutual help). Initiatives regarding

[74] Szokoli (2015)
[75] Thomas and Znaniecki, 5 vol. (1918–20),
[76] Allport (1979)
[77] G. W. Allport (1935), p.810 in Malim T., Birch A. (1998)
[78] UN Report: 'Policy Framework for Active Ageing – 2002, Madrid
[79] National Ageing Strategy, 2009

Alzheimer's and other dementias have already been launched at the international level as well, aiming the foster the equality of opportunities.

The 19/01/2011 resolution of the European Parliament 'emphasises that the dignity of people with Alzheimer's needs to be preserved and the stigma and discrimination against them needs to be eliminated'. Changes in the attitudes of society could be achieved more if services were developed to support patients and their families. There are still significant tasks and opportunities to be done in this field.

Society regards ageing ageing associated with the idea of deprivation, vulnerability, and this is also reflected in the public perception of people living with dementia syndrome.. The social judgement of the disease is also significantly influenced by the current attitudes towards psychiatric patients (according to my experience rejection is typical in Hungary).

Diseases related to the dementia syndrome are currently classified under the umbrella of psychiatric disorders, thus the fear of the patient of exclusion and stigmatisation also appear in the way how the society judges these diseases. The situation of caring families is aggravated by the experienced physical and emotional strain as well, joining the inancial instability as a frequent result of the long-term care, with the consequence of being isolated, which may generate a further stigma on the part of the majority society.

However, there is another approach, as Christine Bryden writes in her book, Dancing with Dementia: '*I think that patients with dementia take part in an important pilgrimage which starts with cognition and leads through emotions to the world of the spirit. I had to realise that only that is important what remains at the end of this journey, and what disappears is not important at all. In my point of view if the society recognised this, patients with dementia would be respected and honoured'*.[80]

According to what relatives say, the majority of opinions about patients with dementia is based on sadness and and sorrowInsufficient knowledge of the disease strengthens specific attitudes attributing silliness or even stupidity to the decline of the brain due to degenerative lesions.

[80] La Doris „Sam" Heinly in. Callone – Kudlacek, 2014p. 19.

Even physicians do that quite often. This 'silliness' is the reason why the environment, friends and neighbours keep distance from the patient.

This attitude is well-reflected by the following detail of an interview:
'- We have been pushed to the periphery of society, we have become excluded. No one ever visited Mum. People cannot handle this situation and feel uncomfortable with a patient with dementia. Many people mistakenly equate dementia with senility. They think that one will simply be stupid. It is true that the patient will not look for logic in the conversation, but it is possible to reflect on what he/she has said and consequently he/she will feel that he/she is talking to the other. This is what makes him/her feel human, as we are social beings; communication is an important part of our existence.'[81]

6.2. 'He Drives me Crazy', but I Love him – How to Accept People with Dementia

When talking to relatives of people with dementia the following sentence is heard almost every time: 'He drives me crazy, but I love him'. The emotional bonding, the plenty of time spent together, memories and joint experiences push the beloved one to the front, and de-emphasize the ill person who produces incomprehensible behaviour and sometimes drives carers crazy. Empathizing with the patient's situation and thinking through the patient's feelings helps understanding and enhances acceptance. The acceptance of a person with dementia is largely determined by how patient relates to his/her own disease. Subsequent to the establishment of the diagnosis, patients accept the disease very differently depending on the person's activities, roles and relationships. Apperception of the disease is also an individual process. It is determined by the personality, basic nature, attitude set and the level of coping ability. Processing also varies from person to person.

It is necessary to become familiar with the expected course of the disease and use every possibility that could slow down the process: a lifestyle change: nutrition, physical activity, and

[81] https://magyarnemzet.hu/archivum/hetvegi-magazin/nepbetegseg-a-demencia-de-nem-ennek-megfeleloen-kezeljuk-3856988/ Downloaded on 15/07/2019
Szokoli (2015)
http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//TEXT+TA+P7-TA-2011-0016+0+DOC+XML+V0//HU&language=HU Downloaded on 29/07/2019
European Parliament resolution of 19 January 2011 on a European initiative on Alzheimer's disease and other dementias (2010/2084(INI))
https://www.felejtek.hu/stigma.html Downloaded on 29/07/2019
https://www.scribd.com/document/382635573/Tringer-Laszlo-A-Pszichiatria-Tankonyve Downloaded on 29/07/2019

learning. Lifestyle change can be a goal on its own but further realistic goals are worth setting. set.

Roles that strengthen identity and increase autonomy should be kept: grandparent, spouse, colleague, friend, chess partner, neighbour. Doing the routine, looking for new tasks, or finding new relationships can help in accepting the disease and in preventing its aggravation. The process of the acceptance of the disease needs honest talk and sincere approach in sharing thoughts and emotions, practising supportiveness. The sense of togetherness, the feeling that 'I can count on my beloved ones' makes the whole process of acceptance endurable.

Besides the acceptance of the disease itself, it is even harder to embrace the person affected by the disease. Instinctive reactions may often fail. It is important in the early stage of the disease not to provide the patient with excessive help. Maintaining self-sufficiency as long as possible increases self-esteem and independence.

Acceptance is greatly supported if the family member (caregiver) exercises listening skills and carefully pays attention to what has happened with the patient, what changes does he/she desires. Patience is also needed when a topic or question is recurrently appearing again and again. Instead of repeating the answer, it can be written down on a piece of paper but shifting the subject may also be a solution.

Another annoying and frequent consequence of the disease is when the patient hides different objects such as a key, documents, money, jewels, etc. Therefore, it is advisable to give a spare key to a close neighbour. When valuables are hidden in the flat, – often perceived by the patient as a theft – it is worthwhile taking time to look for potential hiding places and emptying the trash bins carefully. It is also a good solution to decrease the number of valuables around thus, the chance of disappearance will also decrease. If the patient makes accusations too often, it is advisable to consult the doctor and possibly start medication.

The patient is often unable to recognise certain places or persons. In these situations, kindness and tenderness can help in distracting his/her attention. A familiar set of common activities or a short walk resolving the situation can help.

Regular care and the daily struggle with the problem is a huge emotional burden. A person who did the caring for his mother suffering in Alzheimer's disease has phrased it like 'it feels like sitting on an 'endless emotional carousel'.[82] This sentence is a good description of the condition that many caregivers of Alzheimer's patients experience during their care. Family members affected by dementia also go through a specific emotional pathway when accepting and coping with the disease. It is also true however, that everybody does it differently even if there are many similar situations and conflicts.

It is effective to recall the memories of the past in the moderate or even in the severe phase of the disease by having conversations, reading, and watching photos. Younger members of the family, such as grandchildren, can also join these programs, especially if the grandparent-grandchild relationship has been a strong bond before the illness.

Information about the process of dementia and the likely course of the disease, which can be obtained from the literature or as a member of a fellow community, can help in accepting special behaviours. It is important to know, understand and accept that a loved one is behind the symptoms of the disease. Becoming a caregiver is a learning process that involves wisdom in addition to knowledge, which can also help in dealing with situations that often seem chaotic.

Nowadays, a lot of practical knowledge is available on the various thematic internet sites, blogs, in the peer communities of the social media, where personal experiences can be shared and thanks to the 'impersonality' and the common fate, honest, non-judgemental answers, suggestions, and advice can be found. There are several closed Facebook groups in Hungary, with the active participation of the affected relatives.

It is important that with the progression of the disease personality features and the patient's behaviour change. It is often the case that the affected people deliberatelylly neglect their normal social life as a result of the changes, causing limited social contacts and increased risk of depression. However, meeting a long-time friend or acquaintance can be a great help and motivation.

[82] Horváth – Petrovics,2010

The story of a relative: *'Hello! Yesterday, Mum had to be taken to the doctor for routine examinations. There were many people and we had to wait a lot. There were some people of her age group, ex-schoolmates as well. She talked to them all the way she was enjoying it so much. She felt refreshed for the whole day, told me stories, her mind was clear and she remembered everything. She did things that she had not done for weeks, e.g. undressing, washing I did not have to beg her or argue. She said 'I will be going to wash my face, but watch me if I do it righ.'t 'You know, that my friend, Terus is 2 years older than me and imagine, she still hoes.' The encounter had a positive effect on her. We had such a quiet day very long ago.' (Relatives' Group)*

Besides the decline in the number of social contacts, it is conspicuous when the patient is often nervous, irritable and gets angry easily. Changes include the loss of interest and the neglect of beloved activities, which may make it difficult spending time together. Short-tempered reactions may indicate some kind of uncomfortable situation, an unpleasant feeling or even a medical problem with an organ. The symptoms of apparently causeless anxiety, mood swings or short-tempered behaviour are also parts of the disease and not a series of deliberate actions.

Emotional instability, mood swings – depression – not only make it difficult for patients to control themselves, but they also create difficulties for establishing contacts. The quiet voice, a smile, tenderness and patience conveying our unconditional acceptance and love to the patient are beneficial strengthening the relationship. It may also be important to stick to long-established, accepted name, nickname when addressing a patient.

The experience of a relative: *'My Mum is very rarely aggressive. If it happens then not for long, so we are lucky... anyway she was a very calm, serene and cheerful person before her illness... Most of the time she is still like that... She can rather easily be very depressed… The quickest way to calm her down is kissing/cuddling, holding hands and sitting for a while…'*
(Relatives' Group)

It helps a lot if we do not confront the patient with his/her irrational statements. The following conversation illustrates how it is possible to communicate with a patient while preserving his or her human dignity and reducing his or her sense of shame.

'My dad was funny yesterday. When I arrived, his first question was:

- *Have you brought cigarettes? (He quitted 40 years ago, when my little brother was born…)*

Then he asks:

- *How come that I did not go to work today?*

I replied that he was on leave that day.

He says: - Yeah! Indeed!

After some minutes another question: - Did I build this house? (He moved in two days ago.)

I say no, you did not.

- *But I was there, when it was built, because it is very beautiful!*
- *You were there, Dad, of course, you were. That is why it is so beautiful.*

Short silence, chat about flowers, things like that, and then another unexpected question:

- *Shall we go to the cinema? (I think he has not been to the cinema for 30 years)*

I told him that if he would like to, we will be going.

- *Okay, he says, choose something, but not some shit.*

(Relatives' Group)

Altered sexual behaviour may also be a significant source of conflict. It is not advisable to overreact unexpected approaches and touches, since these are inherent with the disease. It has to be tried to divert the patient's attention and begin another activity. Due to memory loss, a married person with dementia may frequently feel the need to have sex. Rejection may generate anger. Thus, it is advisable to keep distance between each other, and if possible, to sleep in separate rooms at night. This decision is hard to bear emotionally for both members of the couple. It is advisable to consult a professional if the decision goes along with internal tension.[83]

6.3. How do I make my Family (older and younger members) and my Environment Accept the Problem?

Objective and honest knowledge transfer is necessary to tolerate the given situation. After the establishment of the diagnosis, it worth informing the patient and his/her immediate environment (family members, neighbours, friends) on the disease as soon as possible. In the initial stage of the disease, the patient can be involved in the planning of the near and distant future, but only if he/she intends to participate in that. In addition to discussing the details of

[83] Cayton-Graham-Warner (2006)
Szokoli (2015)

the care, the patient's requests should be revealed as well. Furthermore, everything should be written down what may have a significant effect on the future. These seemingly difficult conversations make a significant contribution to decision making in the serious stages of the disease.

Even in the advanced stages of the disease, it is important to talk to friends and family about the disease, its outcome, and the opportunities that can help in slowing down the process and in which they can actively participate. It is also worth discussing the problems that arise during the time spent together. In order to avoid communication difficulties, it is worth telling others, how to communicate with the patient.

Recalling the forgotten contents in the easiest way possible helps a lot in preserving the patient's dignity. At an encounter, when uncertainty is perceptible, the person with dementia can be informed – with the accompaniment of a handshake – where the acquaintance is from. But asking him/her 'don't you recognise me' may be offensive, just like correcting his/her mistakes and completing the missing parts of his/her story.

With family members, relatives, neighbours and friends it is necessary to talk about sentences that do not block the communication with the patient, do not offend him/her, and do not trigger resistance or aggression.

Informing children proves to be a difficult task in many families. Many times the question arises: what does the child understand and what impact does it have on the development of the child if he/she regularly sees the elderly, who has got a medical condition. Children are able to accept people unconditionally and they have a natural relationship with their loved ones, even if their loved ones are ill. Grandmothers and grandchildren may have a mutually good impact on each other and these positive experiences may help not only the acceptance of the disease but also can enhance active life. Considering the age of the children, simple and factual communication may help them understand the situation.

The grandchildren can participate in everyday life via the time spent together (listening to music, playing board games, watching photos, reading books out) which may benefit the patient and the child as well. However, it is vital to talk to children about their feelings and questions. It should also be tolerated when the child does not feel like to be involved in the everyday life

of the patient. Age differences also lead to different approaches and different levels of acceptance. It is also worth discussing with the environment how regular encounters and social contacts can emotionally support the patient. Joint activities, celebrating a birthday or nameday, or a visit of a good friend can greatly boost belonging needs.

By constantly informing family members and friends about the patient's condition, pitiful and surprised looks hurting can be avoided during the encounters. Regular contact also provides an opportunity to communicate how important their support is to the patient, even when it seems unnecessary. In the moderate stage of the disease, the depressive mood of the patient may often manifest in attitudes of distancing as well. It is hard to get close to the patient but common activities such as a walk or concert or planning a meal can help. It should also be recognized and accepted, however, that there will be acquaintances who find it difficult to bear these tense situations. It is worth talking to them about their feelings.[84]

[84] Szokoli (2015)

7. OPPORTUNITIES

Social care has been present in the history of mankind for thousands of years. Supportive communities and available services as options for patients with dementia vary from country to country, but these forms of care are regularly used and available today.

7.1. Alzheimer Café

The Alzheimer Café was founded by a geriatric psychiatrist called Dr. Miesen Beré. The first Alzheimer Café was opened in 1997 in the Netherlands for the families of the people with dementia to let them give a voice on their everyday difficulties without taboos. Other countries have also sought to adopt the good practice. The first Alzheimer Café in Hungary was opened in the town of Győr, while another one was opened in District 15 of Budapest in 2016.

The European model of Alzheimer Café (the Netherlands, United Kingdom, France, Belgium, and Switzerland) works towards enhancing slowing down the progression of the disease and serving belonging needs. It aims to foster information transfer among people affected by the disease and not depriving them from interacting with people. It is important for those concerned to be able to talk openly about the disease without taboos. Meetings are held in community spaces and cafés. In the American model, the emphasis is placed on arts, social and physical environment, and interactions. Gatherings are held in museums and concert halls.

Alzheimer Café is organised by professional practitioners, participants attend the events on a voluntary basis. Participants arrive to the programs whenever they would like to. The presentations are interactive thus, participants can share their own experience and raise their questions. It is necessary to have an expert on the spot who can answer the questions properly.

Alzheimer Café is a friendly community space with pleasant atmosphere, where programs are held from January to May and from September to December once a month. Each occasion lasts for two hours, and they are held on the same day and at the same time for consistency and predictability.

The content of each occasion is compiled to meet the participants' needs. Local media (television and press) are regularly present in order to inform the residents about the events and

to foster social awareness and sensitivity to the issue. If requested, the supervision of the people with dementia is provided during the events.[85]

7.2. Useful Free-Time Activities, Sessions to Maintain and Improve Condition

The daily routine of the patient with dementia should include useful free-time programmes and, and other activities that engage and hold his/her attention at home as well. A patient with dementia may feel ashamed at the onset of symptoms. Consequently, he/she avoids personal contact with old friends and acquaintances, and thus the patient's social relationships are narrowing. It is the responsibility of the caregiver to ensure that the patient's free time is spent usefully.

When organising programs, the individual's interests, abilities, openness, motivation, physical and mental state should be taken into account. Poor evaluation may cause the patient to lose confidence in the caregiver. As a consequence of the overestimation of the patient's abilities, he/she may have a sense of failure, because he/she is not able to perform the given task. When the patient's abilities are underestimated, he/she may say that 'I am not stupid'. (This phrase will often be heard from the patient as the disease progresses.)

The established daily routine should include activities that create a sense of usefulness in the patient. The patient should be encouraged to perform a task through appropriate communication. (e.g. the patient is told that he/she helps to his/her caregiver by carrying out the given task).

When choosing free-time activities, the risk of accident should be avoided while executing the task (e.g. task to be performed by a knife), and the patient's health and physical condition must be sufficient to perform the activity. We can ask the person with dementia to help with the housework if he/she would like to (folding clothes, hoovering, sweeping, doing the washing up, clean the vegetables, water the plants, etc.), even if we know that what he/she is doing is not of the best quality.

It is very important that the work he has done should not be corrected in the patient's presence (refolding the clothes, mopping up, washing up etc.). Our goal is to keep the patient active, making him/her feel that he/she is still a useful member of the family.

[85] http://alzheimercafe.hu/wp-content/uploads/2018/04/Alzheimer-Caf%C3%A9-szervez%C3%A9se.pdf Downloaded on 31/07/2019

Efforts should be made to reach that the make the patient talk during the performance of the activities. The stories told must have been heard several times by the caregiver, but let him/her talk for as long as he is able to. When a conversation is not initiated on his/her own, try to get the patient involved in a topic that are dear to him/her (e.g. whose role was it to tackle the given dohousehold chore in the family when he/she was a child). During the conversation, correcting should be avoided, instead active listeningand directing the dialogue with questions, and supportive navigation is advised.

Tasks that the person with dementia refuses to do should not be forced on! If possible, the cause of the resistance should be revealed. The refusal may be explained by a previously experienced failure.
In order to motivate and inspire the patient to do things encouragementis needed. After the task has been completed expressing praise is gratifying. Success and feeling praised generates motivation of the person with dementia to do the given job.

Therapeutic home assignments are not about improving the patient's abilities, but about maintaining those abilities for as long as possible, which can improve the patient's self-esteem and self-evaluation.

7.2.1. The Improvement of the Sense of Time and Space

The disease also damages the ability of temporal and spatial orientation of the person living with dementia. An exercise to improve temporal and spatial orientation is the following: the patient has to repeat the date (year, month, day, and season) and his/her address several times on every single day.

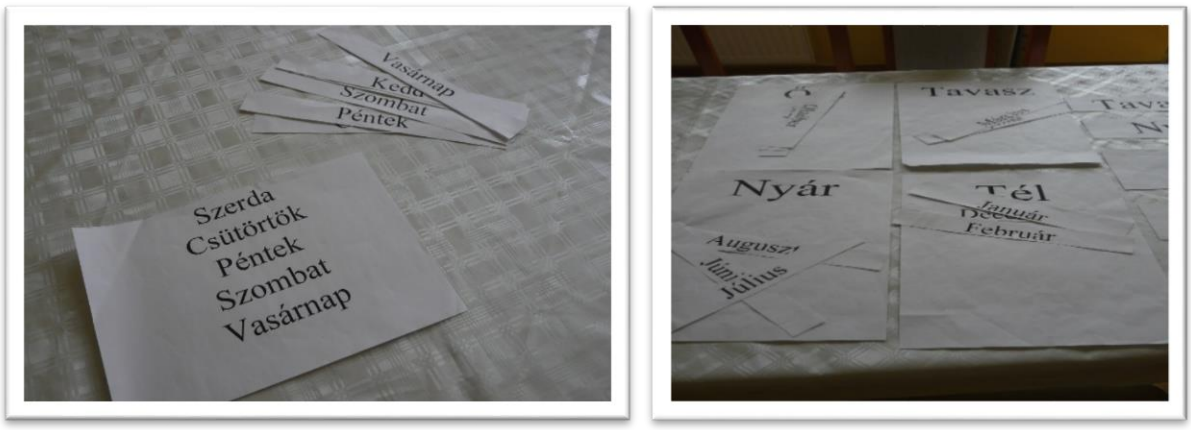

Figure 23: Exercise to improve orientation

7.2.2. Exercises to Improve Perception and Detection

During perception and detection, the senses are used.

Eye

The appropriate colour and shape should be matched. Bright colours should be applied.

Ear

A game with sounds: the person with dementia has to recognise different sounds.

Touch

Familiar objects are placed on the table and covered with a tablecloth. The patient scans the item under the tablecloth and tries to name it.

Smelling, tasting

During the game, the patient must figure out which spice is in the small bowl (causing discomfort should be avoided e.g. smelling pepper).

Figure 24: Game improving touch and perception

7.2.3. Exercises to Improve Memory

The disease damages short-term memory. When completing the exercise one should strive for a sense of achievement. The difficulty of the tasks should be selected according to the severity of the disease (e.g. short poems, word chains, sayings, proverbs, true or false, synonyms, antonyms, polysemies, guessing an occupation by circumscription, conundrums, word-repeating games). The advantage of word games is that they have no device requirements and can be used anytime, anywhere.

7.2.4. Exercises to Improve Thinking

For a person with dementia, logical thinking is difficult. The patient has difficulty in finding causal relationships. By using the ‘smart cube’ game the person living with dementia can be stimulated to think in various ways.

Figure 25: ‘Smart cube’

7.2.5. Exercises to Improve Motor Coordination

As the disease progresses, the motor coordination of the person with dementia gradually deteriorates. In order to maintain the activeness of the patient, it is essential to perform movements that maintain existing motor skills e.g. chair exercises, spine training, seniors’ dance, walking. When selecting the exercises, the physical and health condition of the individual should be taken into account.

7.2.6. Exercises to Improve Fine Motor Skills of the Hands

The fine motor movement of the hand is involved in many activities that are necessary to maintain independence for as long as possible (eating, dressing up, brushing the teeth, grabbing tools). Exercises may include lifting objects, grouping pearls according to their size and colour, colouring, and beading (for the better able patients).

7.2.7. Music Therapy, Sound Therapy

Most people with dementia love to sing old songs. Singing makes it easier for them to recall the lyrics. Listening to relaxing music also helps in relieving tension and has a positive effect on the patient's well-being. During the course of sound therapy, the therapist sounds different sound bowls that help the individual to attain a state of rest. Sounds can evoke memories (e.g. sound of the pouring rain).[86]

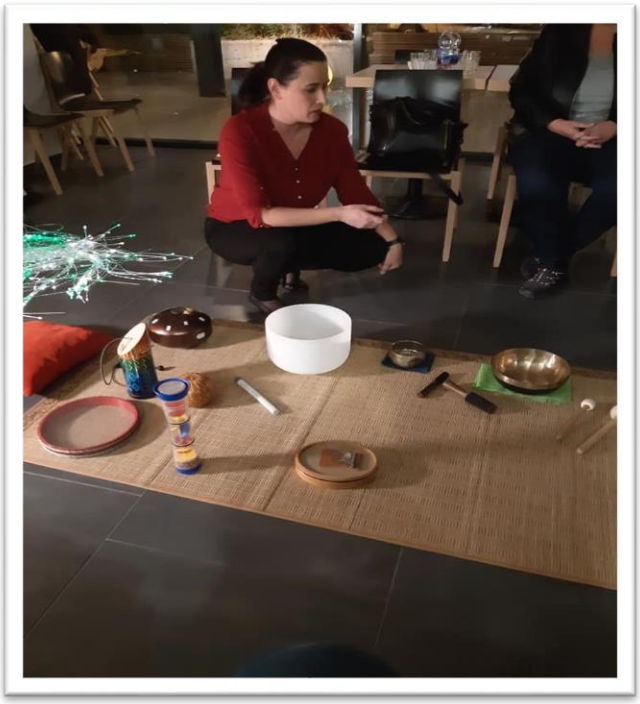

Figure 26: 'Hangpancsi'

7.3. Good Practice:

7.3.1. Local Government of District 15 of the Capital City of Budapest – Relatives' Group

'Again we are deeply helpful, when we risk ourselves as persons in the relationship, when we experience the other person as a person in his/her own right.' *(Carl Rogers)*

The Relatives' Group was established in 2016 in District 15 of the Capital of Budapest, within the Újpalota Child and Family Welfare Centre of the Joint Social Institution (ESZI). It started to operate led by a psychologist and a mental health specialist. The organisation has been in close cooperation with the Alzheimer Café programme. The headquarter of the group is located in the centre of Újpalota. The building is modern, technically well-equipped and well-furnished and at the same time client oriented and provides a pleasant atmosphere for the events. Meetings

[86] https://idosgondozas3.webnode.hu/news/foglalkoztato-terapia/ Downloaded on 20.10.2019

are one and a half hours long and they are organised monthly in the same week when the Alzheimer Café programme is held.

The innovativeness of the programme lies in the complex and holistic approach of the group meetings that people affected by dementia are provided with. Mental health professionals are present at the meetings with offering comfort and understanding. They proceed with exploring topics and emotions, taking into account the particular needs of the group members. The group has a healing power, where the person affected by dementia receives special attention and listening partners.. The professional work of the helpers is characterized by person-oriented approach, cooperative spirit based on trust, and honest communication. After the meetings, reflections, experiences and feelings are shared.

The Relatives' Group meets the social needs of the group members (e.g. acceptance) and helps the participants to achieve the goals. Participating in the group processes helps addressing solving difficulties and blockages that haven't been solved before joining the group. These can be either a care-related task, or an emotional blockage, both will boost the individual's self-esteem after being eliminated.

The group is free to attend, caring family members can join the group at any time. In the group, they can communicate openly with each other and sincerely show their negative feelings as well. The group is meant to be safe space where group members (caregivers) can raise their questions and identify needs for fruitful group discussions. The greatest 'magic' of the Relatives' Group is that over the past three years, friendships have been formed among the members, they have been authentically connected with each other, mutual support has been given to cope with solve difficulties and eliminate blockages.

The purpose of the Relatives' Group is to help, and improve the daily lives of families with dementia. Help them find solutions to the stressful issues that affect them on a daily basis. It also aims to provide space and security for the sake of frank, open, taboo-free conversations with professionals, where stakeholders can share their feelings, desires, and ideas for the future. In the group, the individual feels that he/she is not alone with the problem, because his/her fellows also face similar difficulties and obstacles. The Relatives Group is an opportunity for the affected person to share his/her experiences, successes and failures, and to talk about his/her feelings, relationship with the patient with dementia, and his/her everyday life.

As a result of the regular meetings, the members of the Relatives' Group become more open and they experience the feeling of belonging to a supporting community and find comfort in the feeling of togetherness. Ideally the members of the community achieve a more balanced mental state and reassured adapting to a more problem-solving attitude. . Group members provide each other with mental support. The feeling of 'I'm not alone' develops. Experiences told by the group members may provide individuals with supportive care solutions (e.g. what to do if the person with dementia refuses to bathe, does not want to undergo examination, how to maintain the patient's independence while keeping in mind his/her human dignity, etc.). The members of the group are learning more and more about the disease and their knowledge is constantly expanding and deepening.

Within the group, the individual's self-power is strengthened and multiplied. The group has tremendous retention power. During meetings, important information flows and exchanges that are useful, valuable, and effective in the care process. Each group member is unique in his or her set of values, norms, attitudes and thinking patterns, relationship and communication patterns, experiences, own resources, wisdom, and inner emotions.

The Relatives' Group provides a supportive background for affected relatives and family members. It is located in the modern building of Újpalota Family and Child Welfare Centre. In the comfortably furnished space, the members of the group sit in a circle. It is typical of teamwork that everyone is actively present during the meetings. Initially, the number of the group members way always changing. (The minimum number was 3 and the largest number 12 in recent years.) Effective teamwork can be achieved in small group sessions of 5-7 people. The majority of the members of the Relatives' Group in District 15 provide care to parents, but there are some who cares a spouse or friend.

From the beginning one of the goals is to create a sort of family atmosphere where group members can talk about a given topic without prejudices overcoming the stigmatisation that surrounds the disease. During the encounters, an insight is given into the members' life situation, their role within the family, their relationship and communication patterns, their relationship with the patient and how they cope with their everyday difficulties. Each time relatives report in detail on the health status of the person being treated, the changes observed

in their behaviour, difficulties that appear to be insurmountable, minor or major losses, and relevant happenings since the last time.

Caregivers of people with dementia mainly experience fustrations in their daily routine. Group work focuses on the topic of failure, but doesn't want to neglect what success means to the members. It tries to enhance identifying minor successes and encourage the carers to find the language to communicate about them. Therefore, the concept of success has been clarified at group meetings, and since then, members have repeatedly reported on their own successes how they experience in their daily lives.

As it has been outlined before, an important aspect of caregiving work is respectfulness. During the meetings, according to the stakeholders, relatives help their family members with dementia with devotion and hard work. A lot of times they do what can be expected in a given situation beyond their strength. Many members of the group can effectively 'remedy' the difficulties encountered with creative and unique approaches, and there are ones who really struggle when are facing an unexpected issue that was previously unknown. The flow and exchange of new information, and the sharing of best practices provide the members with support every time they meet.

Experience has shown that as the disease progresses, the patient's condition deteriorates and the physical and mental burden on the caregiver's family increases. It is essential to have a support group where the individual can gather strength until the next encounter.

Due to the lack of leisure activities and me-time, which is typical of overburdened individuals, the professionals in the Relatives' Group provided the members with opportunities through joint programmes to spend their leisure time fruitfully. Members regularly participate in monthly events, which include cultural programs, excursions, joint fishing, and cooking. The patient with dementia also participates in the recreation activities if possible (depending on the length of the current program, the condition of the individual with dementia, etc.). The shared experiences gained through leisure activities have liberating power, and the positive feelings generated affect the physical and mental state of the participating group members.
The Relatives' Group maintains close contact with the district's dementia care institution (the Elderly and Dementia Service) and professionals who provide day care for people with

dementia. During the meetings, the participants receive detailed information on the services available and the possible forms of financial assistance (financial aid).

It is a common practice that group leaders invite external experts to provide group members with knowledge that is relevant to their interests (e.g. caring activities, residential care, issues related to guardianship, home assignments, practical information, etc.). Assisting professionals are constantly participating in different forms of training, workshops (e.g. conference on seniors, lectures by Alzheimer Café, dementia simulation workshop, etc.) to broaden their knowledge on dementia and ageing. As they are practitioners engaged inknowledge sharing, the group members acquire increased and deeper levels of knowledge as well.

Group members communicate openly and frankly even about their deepest feelings, and they have confidence in each other. Trusthas deepened over time, it’s presence can be felt, even the fluctuation of participants has not broken it.

Making a good group work requires active listening and empathic skills, knowing how to pay attention to the other’s reflections, how to interact in ways which ensures understanding and keeping respect. The individual feels safe in that atmosphere of trust. Due to the regular meetings, members of the Relatives’ Group have become more open and the feeling of togetherness has developed. Even close friendships have been forged among group members.

The program's human resource needs are: a mental health professional, a psychologist, and a gerontology caregiver.

Figure 27: Excursion to the town of Székesfehérvár

Figure 28: Group room

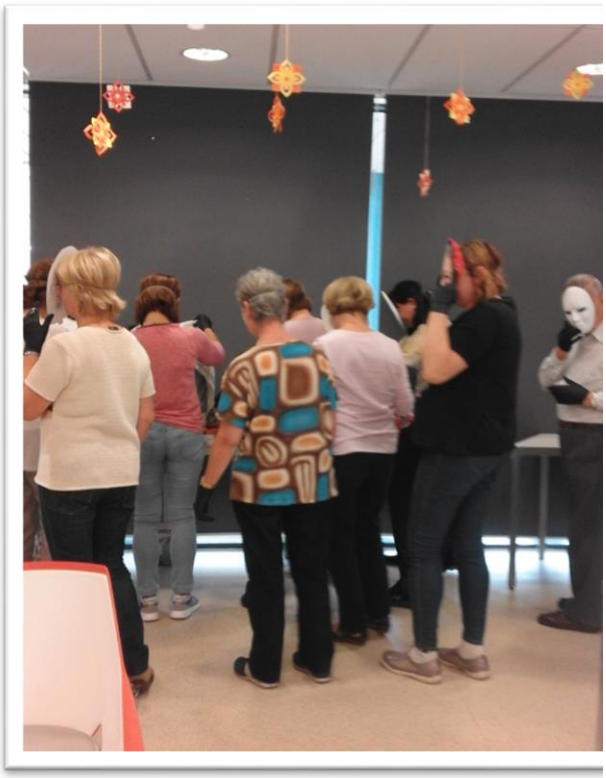

Figure 29: Dementia simulation workshop

Figure 30: Fishing and cooking at Gáti-tó

7.3.2. Good Practice: Local Government of District 15 of the Capital City of Budapest – Dementia Day Care

Name of the good practice:

Dementia day care in District 15 of the Capital of Budapest for people affected by dementia.

In District 15 of the Capital of Budapest a number of families were reported to face difficulties day care provision for a relative living with dementia in their home. Therefore, the socially sensitive "Age-Friendly Local Government" decided to create a dementia day care where the special needs of the residents of District 15 living with dementia can be met. The district's public services (welfare system, health care) conducted a poll about the needs of the inhabitants, and then the local government approved the improvement of the service.

Before the institution opened, the population underwent a sensitisation, (awareness raising) and in February 2016, following the renovation of the Elderly and Dementia Service, it opened its doors to the inhabitants of District 15 living with dementia (as well). The institution is easily accessible, barrier-free thus suitable for the people living with disability as well.

The dementia day care in District 15 is seen innovative because the service operates as an integrated elderly care within the Elderly and Dementia Service. The service is available for a maximum of 12 people at once. Besides the personalised daily sessions for the patients, mental support is available for relatives on request. People affected by dementia (patients and relatives) are dealt with by empathic and qualified professional staff..

The purpose of the dementia day care is to meet the special daytime needs of people with dementia, enabling them to live in their own homes for as long as possible. Spending time in the community prevents the isolation of the individuals. The safe atmosphere of the institution allows tailored activities at high professional level, which help to maintain the individual's condition for a longer period of time and preserve his/her independence for as long as possible. A further aim is to broaden the professional knowledge of relatives in the field of dementia, which will enhance their care duties.

Patients participate in sessions by which the deterioration of their condition can be slowed down, while their mental status can be improved or at least kept on the given level. The everyday life of people with dementia becomes filled with content.

Description of the good practice:

1. The dementia day care at the Elderly and Dementia Service is provided with an appropriate infrastructure, in which the persons with dementia can spend their weekdays in a relaxed and balanced atmosphere between 7.30am to 3.50pm. In this dementia-friendly environment an activity room is provided for creative activities, a parlour for leisure activities (such as talking to each other, watching films) and a dining area. After mealtime, people with dementia do have the opportunity to 'retreat' to the nap room to have a rest. Rooms are provided with pictograms to make orientation easier. The institution has many windows, thus enough natural light is provided for daytime activities.

2. In our integrated day care facility, active seniors usually visit people with dementia. An important consideration when organizing larger programs is that that people with dementia should be able to participate on request, therefore their specific needs are taken into account.

3. Mental health activities are carried out in small groups to meet the needs of people with dementia. The purpose of the sessions is to preserve and enhance existing functions and capabilities. The patients' daily routine includes orientation tasks, workshops that improve the functioning of the senses, group and individual conversations, word games, memory development tasks and physical activities (the improvement of fine motor and gross motor skills). Performing daily activities in a playful manner creates a pleasant and good atmosphere for the participants. For outdoor activities, there is a closed garden to meet the needs of the elderly (tall-seated benches, artificial turf terrace, lawn in the garden, and a parasol).

4. People with dementia may avail themselves of daytime meals. One portion of hot meal is delivered from the kitchen to every patient, including ones with diabetes or biliary disease. If needed, the kitchen assistant purees the food in the kitchen area.

5. Hairdresser and pedicurist are also available for a fee on the spot. If requested, the caregiver accompanies the elderly.

6. Outdoor programmes are also organised, when the people with dementia visit nearby institutions (e.g. market, shopping mall, children's theatre). For the outdoor activities and walks, medical aids (e.g. wheelchair) are provided for patients with reduced mobility. Under the guidance of the staff, patients regularly commemorate or celebrate major events such as Easter, Mothers' Day, Pentecost, 6th of October, 23rd of October, Santa Claus, Christmas. During the events, poems related to the anniversary or celebration are recited together.

7. Relatives are also assisted on demand. It is important to establish and maintain a relationship of trust with them. Family members who provide people with dementia with care can receive

guidance and information from the staff how to apply for residential care, manage issues related to guardianship, and request available cash benefits (social allowances).

8. Permanent sessions during day care for people with dementia

Monday

Morning: physical activity, perception improvement game, 'reality' orientation training,

Afternoon: creative activities, fine motor movements, memory retention, word game, adventure in the realm of numbers,

Tuesday:

Morning: physical activity, playful sessions in the framework of cognitive therapy methods, our dear memories.

Afternoon: listening to music, singing session.

Wednesday:

Morning: senior dance, orientation tasks, memory game, puzzle.

Afternoon: listening to music, creative session.

Thursday:

Morning: physical activity, memory and speech retention exercises, creative session, 'reality' orientation training.

Afternoon: listening to music, watching a movie – discussion about it.

Friday:

Morning: physical activity, listening to tales, memory and speech retention exercises.

Afternoon: 'reality' orientation training, nostalgic session, listening to tales.

With dementia day care, the everyday life of people with dementia are filled with content every day. The special needs of people with dementia are satisfied by dedicated and experienced professionals. The goal is to maintain self-sufficiency as long as possible through a habitual but flexible daily routine, activities satisfying special needs, endeavours to maintain or improve abilities and with time spent in a pleasant atmosphere.

With daily care for the patient with dementia, his/her relatives are relieved of the burden of care. Therefore, they have the opportunity of working during the day, spending free time according to their needs, enjoying recreation and socializing.

Figure 31: Dining room

Figure 32: Nap room

Figure 33: Community room

Figure 34: Creative activity

Figure 35: Joint gymnastics

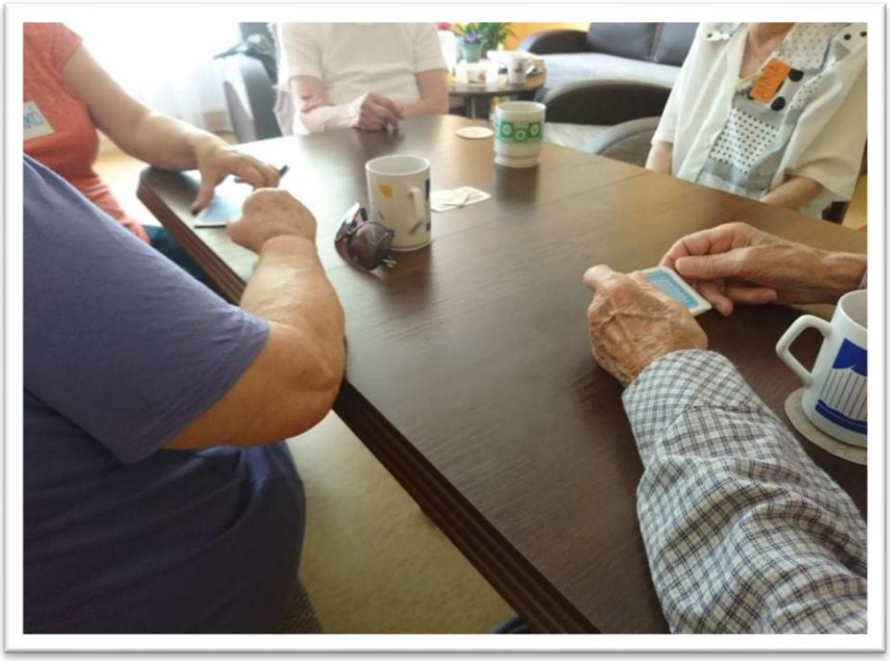

Figure 36: Playing cards

Figure 37: Enjoying the fresh air

8. PROCESSING TECHNIQUES / COPING TECHNIQUES

For individuals, families, relatives and friends affected by dementia syndrome, stigma is associated with diagnosis, so processing techniques may differ from individual to individual. The form and manner of coping with the stressful situation is significantly influenced by the changing situation of families in the modern society.

In today's ever-changing world, the structure of the family has been undergoing profound changes that seriously affect the everyday life of the society. Traditional family roles in the extended families were clear, since there was always somebody assigned with the caring role of different generations. This caring function also strengthened the elderly person's position within the family.

Today, the family's relationship structure has been transformed, individualism, separate lives, and independence has become a priority, promoted by social mobility due to economic constraints. Thus, the ageing generation are left living alone. In addition to economic constraints, the size of the housing stock makes multi-generational cohabitation not favoured. The consequence of all this is an increase in the number of nuclear families. The forms of family cohabitation have changed considerably.[87]

Geographical distance and independent life-styles are serious problems for many relatives. No easy and proven solutions offered. Leaving the usual environment someone has accustomed to is a serious dilemma for the elderly. A concerned relative frequently raises the question: What is I have to do to promote his/her well-being? To what extent shall I pay attention to the existing social ties before making a final decision? To what extent and until which state do existing relationships, friendships and good neighbourhood relations mean safety? What does the cessation of these relationships cause? What will be the effect of moving the elderly person to the offspring's environment?

The slow course of dementia-related illnesses provides an opportunity for the affected person and family to process the disease and prepare for the treatment. After the diagnosis is established, acknowledgement of the illness and managing emotions mean a different spiritual

[87] Somlai (1998)

process for the individual and the close family members There are many factors that influence processing - family, social relationships, lifestyle, hobby, health condition.

Acceptance of diseases requires special processing. In her 1969 book (On Death and Dying), the psychiatrist Elisabeth Kübler-Ross identified five psychological phases of dying: refusal, anger, bargain, depression, and acceptance. Her own work experiences are reflected in the book. The described phases also appear in the psychic processes of incurable patients and their relatives.

Accepting a loved one's illness can lead to similar psychological processes. In the process of accepting the disease, there are struggles, doubts, anger, despair, self-pity, and sometimes the 'why me' feeling. Patients diagnosed at an early stage who have the insight and are fully aware of the course of the disease can experience this process.

From the concerned relatives' perspective, the disease and its process also appear as a loss. They experience a shock facing the sudden change and the process of loss. Occasionally, however, the relative may ignore the developments.

In the next phase, when constrained to face the real situation, the feelings of anger, abandonment, and injustice appear. In this phase, the search for opportunities to change the unchangeable is still sought. Failure is followed by bad mood, sadness, which is part of the process of dealing with the grief of the loss and helps with reconciliation, but the questions about how to proceed also appears. [88]

Patricia R. Callone and Connie Kudlacek emphasize in their book that the task is to 'take care of what is left'. According to their own experience, it needs considerable time and effort from the family members to create the right responses to identify the future ways of care that can prolong that stage for the ill person while he/she remains an integral part of the family.

In their book on dementia, they describe it in a very sensitive way, what sort of tasks will be appearing assigned to the family and the community in the course of the disease. *'In their own way and with the few words they can still use, individuals with dementia are telling us they are*

[88] Callone –Kudlack, 2014

still present - only this presence is extraordinarily unique.' (La Doris „Sam" Heinly in. Patricia R. Callone – Connie Kudlacek; p. 19) This approach can also provide a basis for the family to focus on what is still to be built on, instead of or in addition to the ongoing loss experience. This constant redesigning process with the constant presence is a serious mental burden. Observations show that despite the decline, the emotions of people with dementia are manifested for a long time, such as remembering and responding to love. The caring relatives also confirm this reaction when telling a story.

Caring for the ill relative is burdening for the persons involved. Any long-term illness, the duration and the expected gradual deterioration mean a challenge for caregivers. . Conscious preparation, finding positive things and dividing tasks can help in processing the situation, while giving the opportunity to handle the developments with dignity.[89]

8.1. Do I have to Give up my "old" Life Completely?

Primarily the decision of the family member affected by dementia over his/her own destiny is what counts. That will shape the responses and strategy of the concerned family. In the early stages of the illness, a harmonious and sincere family relationship provides an opportunity to discuss future actions and decisions. To do this, it is essential to be informed about the diseaseand its usual coursebe ready to discuss and plan in detail the expected care tasks and arrangements. This process of addressing concerns and thinking through needs and emotions may provide the basis for new reflections on the choice of accepting or not the loss itself, becoming isolated or opening up for the remaining positive angles.

Characteristics of positive behaviour are t:

- treating our sick relative as an adult,
- when communication is difficult, trying to find other forms to make the expression simple,
- activeness should be maintained for as long as possible, avoid overcaring in order to maintain self-sufficiency, ' doing the tasks together with him/her, not instead',
- remain active participants in regular family events and, even in times of hardship, commit to being together without shame or judgment,
- the difficulty in movement will not be an obstacle to attending different events.

[89] Szokoli (2015)

During joint activities, when the short-term memory is noticeably declining, the emphasis should be placed on evoking the long-term memory by watching photos, watching movies or listening to music. Naming objects in the dwelling can be effective in maintaining language skills. Activeness can be maintained by regularly performing pre-disease activities such as needlework, knitting, crocheting, drawing, or painting.

The abandonment of "old life" by the caregiver is not an issue if the family members are willing and able to undertake some of the caregiving duties, even temporarily, thereby enabling the caregiver to obtain his/her mental support by spending some me-time. It is the responsibility of the caregiver to map out all the health and social services that can provide help in the everyday life, particularly when the family is overburdened or far away. It is not necessary to make a change if the care activities are performed by an external actor. It is equally important to find communities - churches, neighbourhoods, communities of common open to join - or strengthen existing bonds that can provide external relationships and support in everyday life.

Selecting the place of care is also a serious decision in family's life. In many cases, the current family life can limit and complicate the day-to-day relationship and care process. Visits, care, and nursing are organized very differently in the municipalities. Patients with dementia need stability, so staying in their own environment is encouraged.
The precondition for maintaining the habitat as long as possible when there are huge geographical distances does matter on the financial and income situation of the patient and the family, also determining the possibility of purchasing services even without limits. One of the most decisive forms of giving up "old" life is when in order to care for the patient and maintain the habitual environment, the relative care giver moves to the patient for the period of nursing, which can take years. Moving the ill relative to the home of the caregiver is a similarly difficult issue. Both solutions require a completely new operation from all stakeholders and, are optimally preceded by deliberate joint decision or conscious preparation.[90]

8.2. Social Groups

In the early stages of the disease, even the affected person's goal is to get active ageing. Knowing the condition, it is essential to maintain regular activities - work, social life, volunteering - and maintain existing social relationships. Every new contact may delay the

[90] Szokoli (2015)

process of the disease. Artistic activities are gaining popularity, many activity groups offering arts and crafts have been initiated recently for older adults, dancing (senior dance) is also a great opportunity to remain active, and expand social relationships in a non-stigmatizing open social space.

The primary task of family members in the early stages of the disease is to monitor opportunities for gaining knowledge and support. It is worth looking for and using all the learning offers (on the theme of Dementia)in the vicinity or systematically searching webcontent on the internet to get informed and following the numerous social media sites focusing on this theme.
Another option is joining or forming a self-help community based on common fate, where in addition to experiencing a sense of community, the opportunity is provided for learning the best suitable coping strategy, and for spending some me-time. Groups are usually open for newcomers, while closed groups require a minimal entry procedure.

In many cases, the main obstacle for carers to participate in community programs is the organization of the care for the patient who should no longer be left alone. The well-functioning Alzheimer's Cafe is also inaccessible to many caregivers due to the difficulty of organizing supervision.[91]
Recognizing the constraints of nurses and carers, there are emerging social places offering supervision service for a while for the people with dementia.

8.3. The Elimination of the Sense of Guilt

Dementia is a long-term illness in which caregivers face under severe mental strain. Gradual exertion, 24-hour standby, and then active nursing and caring, along with mental strain, means heavy physical work and thus exertion. This mental and physical strain makes the protection of carers and the organization of leisure time even more important.

It is a frequent question of the carer whether he/shecan trust the loved one to someone else. However, the relaxation and proper rest is a must that creates the basis for the caregiver's duties to be sustained without further injury. Outsourcing may be a solution, but in many countries there is only a short-term form of care service provided where the patient can be placed for a week or two.

[91] Szokoli (2015)

Changes in the patient's condition and mood can be the source of many conflicts. When dealing with seemingly unjustified aggression - shouting, opposing, battery - the caregiver often feels guilty. Experience has shown that caregivers may feel guilty for several reasons. Many times the caregiver feels that his or her support is inadequate and the care given is not sufficient. This is because the caregiver does not always get positive feedback from the person with dementia, and in some cases even the self-help groups can confuse the caregiver as well. Consequently, the caregiver may ask: 'Am I doing something wrong?' It must be accepted that there is no "one size fits all" care for each individual situations and no such as the perfect carer.

Within the family, there may also be a sense of guilt stemming from a relationship conflict before the onset of the disease. Previous grievances, criticism or insults may increase the sense of guilt. If possible, these conflicts should be discussed and clarified so as not to burden the relationship.

Wrath and anger encountered during long-term care also generate a sense of guilt. This stressful situation arises because difficult circumstances, poor communication and lack of feedback that can make the carer angry and frustrated. In such a tense situation, it is worth leaving the room for a short time, signalling to the patient that he/she will not be left alone for long. The latter is important because unexpected loneliness can cause further negative feelings in the patient.
In addition to the many and difficult care processes related to dementia, one of the biggest questions is how long the patient can be cared for at home. The need for 24-hour care poses a serious dilemma for families who, due to their physical distance or lack of financial resources, are unable to provide long-term care at home. In this case, the compulsion of institutional placement means guilt. This form of service does not mean that the relationship is broken, on the contrary, it is even more accepted in institutions that relatives perform caring duties.

In most cases after the death of the patient, the caregiver feels the pain of loss but at the same time he/she feels relief as well, which generates the sense of guilt. Relief is a normal reaction after an extremely strained period. It is worth talking about feelings and keeping in mind that the processing of loss and grief varies from person to person.[92]

[92] https://www.alzheimers.org.uk/blog/guilt-dementia-how-manage-guilty-feelings-carer?page=1 le
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8.4. Eliminating and Overriding Habits

Changes in his/her own daily routine is also essential if the caring relative intends to perform long-term caring in an adequate mental condition. Getting ready to accept that after some time the caregiver will be the most important person for person with dementia, this fact also demands the caregiver to maintain his/her physical and mental condition. It needs acquiring the right knowledge, giving time to think trough realistically the whole process, the expected changes and the capacities to perform.

Numerous emotions appear during the course of the disease. Sometimes joy in a better period, cheerfulness, other times anger, dissatisfaction, guilt. The processes within the family are within the scope of intimacy and in many cases it is difficult to open towards the outside world. This closed, tradition-based behaviour will only result in the isolation of the caregiver, thus it is necessary to share feelings with their confidants, be it a family member, a friend or a supportive member of any other (i.e.the religious) community.

Everyday tasks and failures have a significant impact on the caregiver. Positive attitude and the humour can help in overcoming the crisis.

In addition to continuous and unselfish assistance, maintaining the caregiver's health is essential. Nursing requires proper activeness, nutrition and rest to prevent fatigue. Planning can create opportunities for freedom as well as emotional support.

In order to carry out the tasks, the operation of family relationships, the involvement of family members and relatives in the continuous caring tasks is also essential. Joint preparation can greatly help this process.

Commitments should be voluntary, and everyone can decide which area of caring is suitable to his/her capacities and available free time. Someone will offer reading, an another one will contribute with selecting photos to talk about with the patient, while the caregiver is involved in everything else, even the administration has to be taken care of beside recharging batteries in the assigned me-time. Someone will help in going for a walk, someone else will help in bathing. Individual situations call for individual solutions.[93]

[93] Szokoli (2015)

9. END OF LIFE CHOICE

'We were born to this world alone and we will leave it alone. And how many times we need to be alone in between – simply because there are minutes and hours that cannot be halved! When we need to be alone!' *(Endre Gyökössy)*

Old age is the last cycle of life. At this stage of life, the opportunities for the elderly person are narrowing and losses are cumulative. Can we talk about successful ageing with all this in mind? How can an old person prepare for the last moments of life? Can we prepare for the significant change that everyone's life is finite, without exception? What is more, it is also important how an individual thinks about losing not only his/her loved ones but losing him/herself? Can he/she make the decision to prepare for the end of life choice? Is there a choice at the very end of life? There may be many questions to raise, but it is sure that everyone has a different attitude to death, and everyone is afraid of the thought of death or even dreading death itself.
Facing losses in old age is perhaps the most difficult challenge. Awareness, planning, balance of opportunities and abilities, and acceptance help us to overcome the difficulties and obstacles of our lives.

Ageing as a process providing an opportunity to begin preparing for old age in the middle stages of life, which may prevent the emergence of a crisis by mobilizing various energies (physical, mental, spiritual). In order for an individual to experience ageing as successfully as possible, it is important to look for and perform tasks and actions that make sense in someone's life. Not only social interactions, mental activeness, keeping fitness, preserving the sphere of intimacy all contribute to healthy ageing. .

At this stage of life, the elderly person formulates and asks questions: 'Have I lived the right way?', *'Have I done what I originally planned to do?','Have I left an imprint in the world?', and 'Were my deeds good ?' etc*. If the elderly gets answers to these questions that will satisfy him/her, a sense of completeness will be achieved. Erikson describes this with the concept of 'self-integrity'. The integrated person experiences the meaning of life, who understands and accepts what he has done, looks back with satisfaction at what he has left behind. The elderly person with his/her knowledge, wisdom and experience is a tremendous asset for society and for the younger generation.

‘Wisdom is found with the elderly, and understanding comes with long life.’ (Job 12:12)

Concerning end-of-life crises, decisions made at earlier stages of life are based on the quality of facing with them. Unresolved difficulties, crises and lack of coping strategies can make this period very difficult. One has a peculiar approach to the finality of his life, to his death. This peculiar attitude makes it difficult to make end-of-life decisions in time.

In the previous chapters, it has been mentioned several times that when the onset of the initial symptoms occurs, a specialist should be consulted to make the diagnosis. After the diagnosis of dementia, the course of the disease can last for many years and during the course of the disease significant changes occur in the affected personality’s quality of life, judgement skills, disease awareness and thinking.

The patient in the late stages of dementia will not be able to exercise his/her right to self-determination and will not be able to make competent decisions. Early diagnosis allows the patient and family to make timely decisions that can affect their lives.

The patient may dispose of:

- the guardianship procedure
- the guardian
- his/her placement
- money management
- health care management,
- his/her bequest
- his/her funeral
- etc.[94]

[94] https://eletveg.hu/hu/eletvegi-dontesek/ Downloaded on 18/07/2019

10. CLOSING REMARKS

Every stage of life has its own task to solve, and old age is no exception. As age advances, vision and development opportunities will provide a narrower cross-section. Skills also change, they decline and wither and crises may make this stage of life more difficult.

It is difficult to accept the depletion of resources and the narrowing of opportunities for young and old alike. The purpose of this teaching material is diverse. In addition to sensitising society, it also aims to achieve shaping intergenerational cooperation.

Professionals (health care and welfare), NGOs, churches and charities are indispensable participants of care. Developing their capacities through educative and supportive networks of cooperation is a great asset ensuring better life options for the people affected by dementia.
In addition to helping the caring families, the transfer of knowledge also aims to increase the tolerance of the community in order to preserve the autonomy, self-determination and human dignity of the patients concerned. It is also a clear goal to urge every affected people to start preparing for active ageing consciously and in time, because ‘here and now’ will shape there and then’.

References

Callone, Patricia R. –Kudlacek, Connnie (2014): Alzheimer a családban, Zafír Press

Cayton, Harry – Graham, Nori – Warner,James (2006): *Alzheimer-kór és a demencia egyéb fajtái,* Budapest:Springmed Kiadó Kft

Csürke József – Vörös Viktor – Osváth Péter – Árkovits Amaryl (2014): *Mindennapi kríziseink,* Budapest: Oriold és Társai Kiadó

„Demencia és rizikócsökkentés: a védő és változtatható tényezők analízise" – a Nemzetközi Alzheimer Társaság világjelentése, 2014.09.17. London

Az Egészségügyi Minisztérium szakmai protokoll (2006, 2007, 2009) *A demencia kórismézése, kezelése és gondozása* **Készítette:** A Pszichiátriai Szakmai Kollégium

Füredi János (ed.) – **Németh Attila** (ed.)(2015): *A pszichiátria magyar kézikönyve*, Medicina Könyvkiadó Zrt.

Hennezel, Marie de (1997) : *A meghitt halál,* Budapest: Európa Könyvkiadó

Horváth, Szilveszter – Petrovics, Zsuzsa (2010): *Alzheimer nyavalya,* Budapest*:* Garbo Kiadó

Jeszenszky Zita (2016): Demens idősek ellátásának irányelvei. Kapocs, 6.sz.

Juhász Ágnes (2018): *Demencia szakápolás,* Budapest: Balassi Kiadó Kft **Kübbler-Ross, Elisabeth (1988):** *A halál és a hozzá vezető út,* Budapest: Gondolat Kiadó

Malim T. - Birch A. (1998) Attitudes. In: Introductory Psychology. Palgrave, London

Papp,Katalin – Újváriné,Siket Adrienn (2014.): Az egészségügy és az ápolás általános alapelvei. Debrecen: Debreceni Egyetem Egészségügyi Kar Szabó Lajos **(2011):** *Időskori demenciák családi, társadalmi és pszichológiai vonatkozásai,*Budapest*:* Akadémia Kiadó

Szirmai, Imre (2011): Neurológia. Budapest: Medicina Kiadó

Szokoli, Erzsébet **(2015):** *Az idősek gondozása otthon,* Kézirat (2015)

Tringer László (2010): A pszichiátria tankönyve. Budapest: Semmelweiss Kiadó

Jeszenszky Zita: Demens idősek ellátásának irányelvei. file:///C:/Users/Fito/Downloads/jeszenszky-zita---demens-idosek-ellatasanak-iranyelvei%20(2).pdf

http://aek.gov.hu/rovatok/kozpontrol/kozpontrol/alapdokumentumok/mees/download/mees.pdf

http://alzheimercafe.hu/wp-content/uploads/2018/04/Alzheimer-Caf%C3%A9-szervez%C3%A9se.pdf

http://aok.pte.hu/docs/phd/file/dolgozatok/2002/Kordas_Mariann_tezisfuzet.pdf

https://eletveg.hu/hu/eletvegi-dontesek

https://eletveg.hu/hu/az-eletvegi-idoszak

https://esem.hu/szotar/feherallomany
http://foh.unideb.hu/sites/default/files/upload_documents/magyar_gerontologia_2.7.pdf,
http://foh.unideb.hu/sites/default/files/upload_documents/magyar_gerontologia_2.7.pdf,
https://hospice.hu/docu/EuMin-szakmai-iranyelv_terminalis-allapotu-daganatos-hospice-palliativ-ellatasarol.pdf
https://hu.easymedicaldiagnosis.com/generalizovannaja-cerebralnaja-atrofija-2-stepeni.htm
http://idosgyogyaszat.hu/upload/idosgyogyaszat.hu/files/131215_A_vascularis_dementia_es_a_leggyakoribb_tarsbetegsegek_terapiaja.pdf
https://idosgondozas3.webnode.hu/news/foglalkoztato-terapia/
https://inda.info.hu/uploads/dokumentumok/gondozasi_kornyezet.pdf
https://inda.info.hu/uploads/dokumentumok/pszichopatologia.pdf
https://inda.info.hu/uploads/dokumentumok/interprofesszion%C3%A1lis_demens_ell%C3%A1t%C3%A1s%20alternat%C3%ADv%C3%A1i.pdf
https://magyarnemzet.hu/archivum/hetvegi-magazin/nepbetegseg-a-demencia-de-nem-ennek-megfeleloen-kezeljuk-3856988/
http://neurosurgery.pote.hu/idegseb/dat/isebjegyzethu/f4.html
http://semmelweis.hu/igazsagugy/files/2012/06/18_mszlev.pdf
https://www.alzheimers.org.uk/blog/guilt-dementia-how-manage-guilty-feelings-carer?page=1 le
https://www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia/creutzfeldt-jakob-disease
https://www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia/mixed-dementia
https://www.alz.org/help-support/caregiving/daily-care/daily-care-plan
https://www.alzheimers.org.uk/get-support/daily-living/your-relationships
https://www.alz.org/help-support/caregiving/safety/
https://www.alz.org/help-support/caregiving/safety/home-safety
https://www.alz.co.uk/research/WorldAlzheimerReport2019.pdf
https://www.betterhealth.vic.gov.au/health/ConditionsAndTreatments/dementia-safety-issues
https://www.dementia.org.au/files/helpsheets/Helpsheet-AboutDementia01-WhatIsDementia_hungarian.pdf
https://www.drdiag.hu/kereso/diagnosztika.adatlap.php?id=93523&name=Demencia-Parkinson-k%F3rban-%0D

http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//TEXT+TA+P7-TA-2011-0016+0+DOC+XML+V0//HU&language=HU
https://www.felejtek.hu/mi-a-demencia.html
https://www.felejtek.hu/stigma.html
https://www.mayoclinic.org/diseases-conditions/lewy-body-dementia/symptoms-causes/syc-20352025
http://www.mek.oszk.hu/02000/02009/02009.htm
http://www.miet.hu/hir/39459/alzheimer
https://www.nhs.uk/conditions/dementia/relationships-and-dementia/
http://www.parkinson-tarsasag.hu/upload/parkinson/document/jakabkat.htm
https://www.scribd.com/document/382635573/Tringer-Laszlo-A-Pszichiatria-Tankonyve
https://www.tankonyvtar.hu/hu/tartalom/tamop425/0005_03_a_kommelmelet_alapjai_scorm_02/32_a_kommunikci_fogalma.html
https://www.tankonyvtar.hu/hu/tartalom/tamop425/2011_0001_524_Neurologia/ch02s05.html
https://www.verywellhealth.com/is-it-alzheimers-disease-or-vitamin-b12-deficiency-98738
https://www.verywellhealth.com/normal-pressure-hydrocephalus-98842
https://www.webbeteg.hu/cikkek/endokrin/12572/pajzsmirigy-betegseg-es-tunetei
https://www.webbeteg.hu/cikkek/demencia/14913/a-pick-betegseg
https://www.webbeteg.hu/cikkek/demencia/21147/creutzfeldt-jakob-kor
https://www.webbeteg.hu/cikkek/demencia/22441/a-parkinson-koros-demencia-es-a-lewy-test-betegseg
https://www.webbeteg.hu/cikkek/egeszseges/3714/amit-a-b12-vitaminrol-tudni-kell

Annex I.

METHODOLOGICAL GUIDE

Prepared for lectures based on the 'S.O.S. Dementia' teaching material.
Modifications based on the experience of the pilot education are included.

Goal and target group:

The overall purpose of the teaching material is to transfer knowledge, to handle situations in a personal way, to sensitize society to the problem of dementia, and to enhance acceptance, tolerance as a social asset for those affected, their families and their caregivers. A further aim is to inform and support the affected family members, to pass on their experience, to process their experiences, to guarantee the autonomy of the patients concerned as long as possible and to preserve their human dignity. The target group consists of families affected by dementia plus – due to the openness of the programme – the still active generation as well.

Because of the specificity of the topic, people who are knowledgeable in the field, especially health professionals with a good knowledge of the social and the service environment, are recommended for **teaching the material**. Another important aspect, due to the cooperative training model, is the experience of a trainer and the skills of a team leader. (Minimum 60 hours of coaching or 120 hours of team leader experience is required.)

When learning the material it is important to bear in mind that in adult learning, in addition to theoretical knowledge, one can build on previous experience. Through the transfer of knowledge, the participants gain knowledge and skills in the learning groups, allowing the affected family members not only to learn about the course of the disease, but also to process the disease through their own experiences.

Information for the organisation of the training:

- diversity in terms of qualifications and involvement should be pursued in the formation of learning groups,
- The heterogeneous group needs more preparation and attention, but in terms of effectiveness, it may have many benefits in terms of processing and transferring their own experiences,
- efforts should be made to minimize absenteeism,
- It is recommended to consider joining a given learning group, considering the interrelation of topics and group dynamics.

Group size:	8-12 people / 1 group leader-instructor (pilot training has proved that one group leader can control a group of this headcount)
Location:	1 group room with the adequate number of chairs, natural light, ventilation
Device requirements:	Flipchart, papers, pens, markers, laptop, projector
Duration:	60 hours
Theory/practice ratio:	1/3 – 2/3 (20 hours theory – 40 hours practice)
Certification:	unique certificate

As with all education, the development of competence is also the goal of the **learning process**. Acquirable competencies during the training are as follows:

Knowledge

- general theoretical knowledge about the main characteristics of the different types of dementia,
- getting familiar with the stages of the disease and the accompanying symptoms,
- acquiring the necessary caring activities,
- learning about psychic strain and stress relieving opportunities.

Ability

- to perform tasks,
- to understand the processes of the disease,
- to treat the symptoms of the disease,
- to communicate efficiently,
- to treat aggression.

Attitude

- empathy,
- openness,
- tolerance,
- acceptance.

Responsibility

- cooperation with family members, caregivers and nurses,
- independence during activities.

Learning forms and methods

The learning forms and methods outlined below can be varied by considering the content of the teaching material and the composition of the group. Emphasis should be placed on practice during the training.

Lecture

- the instructor explains the teaching material logically and in detail.

Consultation

- dialogues and discussions in small groups with the aim of deepening the existing and the newly acquired knowledge.

Presentation

- given topics are first discussed in groups then presented individually or jointly. Opportunity is given to raise questions and reflect on what was heard.

Discussing topics individually and in groups

- tasks are performed either individually or in groups.

Presentation

- individual presentations of the topics, followed by the reflections of the group members.

Illustration - film

- participants watch the film, then it is discussed in pairs, small groups or by the group as a whole. It is important to process emotions, internal tensions, and to give vent to one's own experiences.

Suggested methods for processing each chapter of the teaching material:

2. Dementia
   - Lecture
   - Presentation
   - Processing in small groups

3. The recognition of dementia, facing the disease
   - Illustration – film
   - Processing in small groups

4. Providing care for a patient with dementia
   - Lecture
   - Consultation
   - Illustration

5. Changes in everyday life
   - Lecture
   - Consultation

6. The 'person with dementia is problematic'
   - Illustration – film
   - Processing in small groups

7. Opportunities
   - Presentations, own good practices
   - Processing in small groups, presentation in front of the whole group

8. Processing techniques
   - Processing in groups
   - Presentation

9. End of life choice
   - Processing in groups
   - Presentation

References:
https://ofi.hu/tudastar/problemak-kerdesek/oktatasi-modszerek Downloaded on 19/10/2019
https://www.tankonyvtar.hu/hu/tartalom/tamop412b2/2013-0002_egeszsegugyi_szakmodszertan/EG/segjs43g.scorm Downloaded on 19/10/2019

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