



UnderstAid a platform that helps informal caregivers to understand and aid their demented relatives

UnderstAid – platforma, która wspiera, pomaga zrozumieć i pomóc opiekunom w opiece nad krewnym z demencją

Review of the literature

by

Ewa Mojs, Włodzimierz Samborski, Michał Musielak, Jan Domaradzki, Katarzyna Warchoń-Biedermann, Agata Bednarek, Katarzyna Głodowska, Elżbieta Skorupska, Roksana Malak, Bartosz Grobelny

Edition: Ewa Mojs

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11. INTRODUCTION

EU carries out a policy which helps to protect and disseminate mental health, increase awareness of such matters and create European-wide bases for cooperation and exchange of good practices at a governmental and sectoral level, as well as political relations, practical solutions and scientific research. Mental health should be protected at any age and special care should be provided for people suffering from neuropathy and for caregivers for elderly patients. For the past few years the number of episodes of neuropsychiatric conditions has been growing, forcing the constant increase in expenditures on health protection and the necessity to take effective actions against social exclusion, stigmatization and isolation of patients and their caregivers. This report constitutes a part of a research and development programme which is aimed at devising means which would improve the quality of care for dementia patients and support their caregivers in informational, technological, emotional and social areas.

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Partner 8: Ortopedyczno-Rehabilitacyjny Szpital Kliniczny nr 4 im. W. Degi (ORSK, Poland)

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1. Ageing process of societies

1.1. Introduction

The ageing process is a physiological mechanism which becomes evident with age. As the biological activity of a human body decreases, its ability to regenerate and adapt becomes lower, which results in malfunction of body structures, i.e. cells, tissues, organs and systems, as well as increased susceptibility to the diseases of circulatory system, nervous system or tumours. Involutional changes and ailments characteristic of the discussed age manifesting themselves in the ageing process correspond to previously existing health problems, which leads to the occurrence of phenomena typical of elderly age: multiple morbidities, polipharmacy and serious geriatric problems.¹

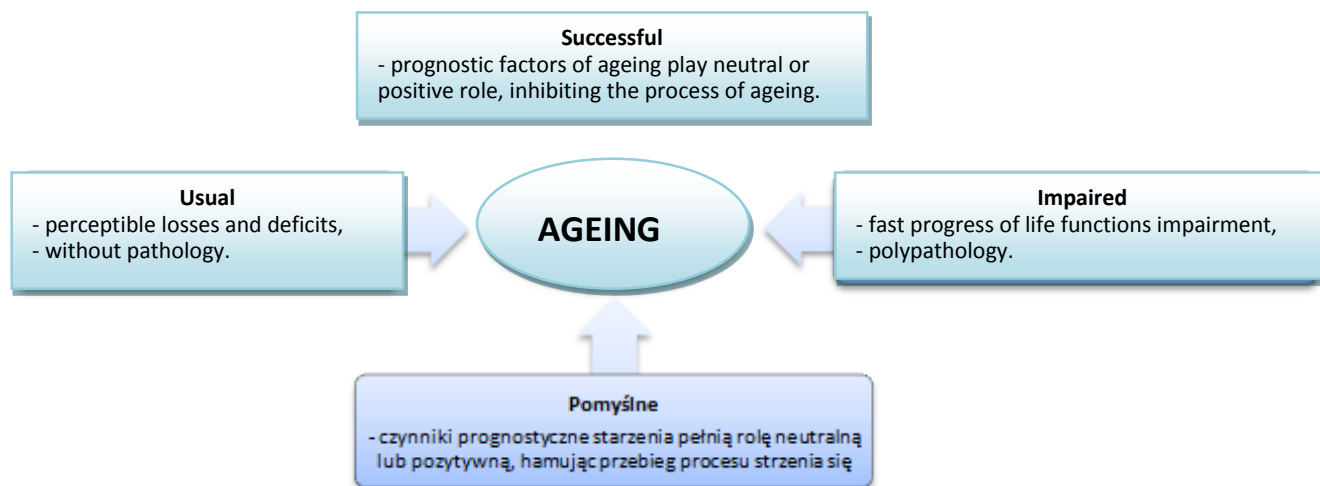


Diagram 1. Models of ageing

Source: M. Muszalik, K. Kędziora-Kornatowska, T. Kornatowski, Successful Ageing Programme – Prevention of Elderly Age Ailments and Conditions, (in:) Successful Ageing in the Perspective of Social Sciences and Humanities, joint publication edited by J. T Kowaleski i T. Szukalski, Łódź 2008, p. 41.

¹ M. Muszalik, K. Kędziora-Kornatowska, T. Kornatowski, Successful Ageing Programme – Prevention of Elderly Age Ailments and Conditions, (in:) Successful Ageing in the Perspective of Social Sciences and Humanities, joint publication edited by J. T Kowaleski i T. Szukalski, Łódź 2008, p. 41.

The so-called geriatric giants are the chronic and pluricausal syndromes leading to disability, loss of independence of the elderly and, in consequence, becoming a burden on caregivers. Apart from conditions such as impairment of sphincter control, balance and locomotion (which causes tipping over), sight and hearing impairments, there also occur psychopathological syndromes: dementia, depression or different types of mental confusion.²

Therapy and the process of diagnosis of pathologies suffered by elderly patients require knowledge about various aspects of ageing and the consequences of this process, as well as the expertise in symptomatology of conditions typical of the elderly, which frequently are too non-characteristic and develop completely differently in young people. Therefore, the present-day seniors should be provided with as active, comprehensive and professional care as possible in order to maintain and promote a health-oriented lifestyle, prevent pathologies and effectively treat existing ailments. Moreover, the role of such care is a close cooperation with patients caregivers and support in exceptionally difficult moments in their lives.³

1.2. Demographic processes in Europe

Europe is undergoing demographic and epidemiological changes of great importance, which shape its future needs in respect to health promotion, disease prevention and care. Due to rapid ageing of Europe's population the pathological patterns are changing, and in consequence, create a need for new solutions in health protection and social security sectors.⁴

Considerable improvement of European populations health witnessed during last decades led to the increase of life expectancy, which currently amounts to 76 years for both men and women. It is mainly the result of prevention and elimination of some of the death causes, as well as progress achieved in counteracting risk factors and the improvement of social, economical and living conditions.⁵

² M. Muszalik, K. Kędziora-Kornatowska, T. Kornatowski, Successful Ageing Programme – Prevention of Elderly Age Ailments and Conditions, (in:) Successful Ageing in the Perspective of Social Sciences and Humanities, joint publication edited by J. T Kowaleski i T. Szukalski, Łódź 2008, p. 41.

³ J. Derejczyk, A. Jakrzewska-Sawińska, A. Jóźwiak, K. Wieczorowska-Tobis, Z. Woźniak, Standards of Medical Services in Geriatric Medicine. Suggestions, 2003, p. 2.

⁴ The European health report 2012: charting the way to well-being, World Health Organization 2013, p. 1.

⁵ The European health report 2012: charting the way to well-being, World Health Organization 2013, p. X.

In 2011 the population of 53 European countries reached nearly 900 million, which constitutes an increase of 5% in comparison to the year 1996. According to demographic forecasting made for the period beginning in 2010, in the upcoming decades the population will not change significantly as a whole, however, the population of particular countries will decrease. Factors responsible for this tendency primarily include lower birth rates and fertility rates below 1.75 (not guaranteeing a simple replacement of generations) together with relatively stable or slowly increasing mortality rates and migration rate. A decrease or a negative value of population growth rate is being documented in the countries of Central and East Europe since the early 1990's till the beginning of the new century.⁶

The population of the Old Continent is ageing rapidly. By 2010 approximately 15% of the total population reached the age of 65 years and more. These numbers present the growth of population at retirement age by nearly 30% in comparison to the year 1980. The said age group is the fastest growing population segment. The particular countries show major differences in this respect nevertheless, according to the forecast the discussed age group will constitute over 25% of the total population of Europe by 2050.⁷

An increasing number of Europeans is reaching the age of 65 years. Mean life expectancy for the age of 65 years is 15.5 years on the average, and it is expected that elderly women will live longer than elderly men by almost 4 years. The similar situation applies to the mean life expectancy at the moment of birth: in 2010 men have not yet reached the life expectancy amounting to 65 years, which was reached by women in 1980. Considerable differences between men and women exist also in the populations of particular countries.⁸ Diagram 1 presents the mean life expectancy of Europeans in the 2006-2010 period.

⁶ The European health report 2012: charting the way to well-being, World Health Organization 2013, p. 2.

⁷ The European health report 2012: charting the way to well-being, World Health Organization 2013, p. 2.

⁸ The European health report 2012: charting the way to well-being, World Health Organization 2013, p. 7.

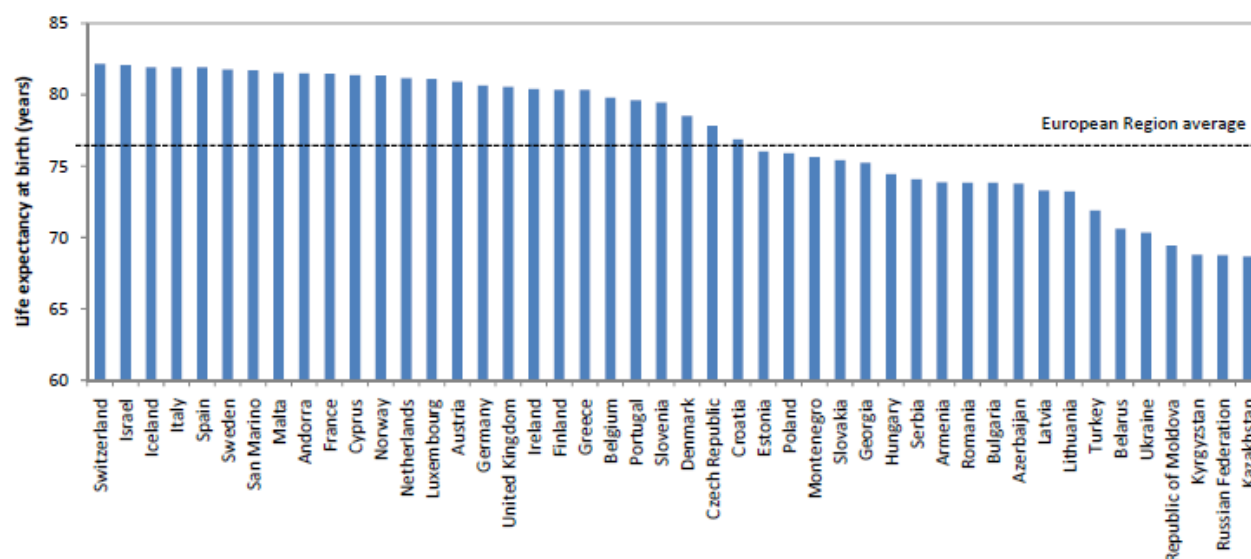


Diagram 2. Mean life expectancy in Europe in the years 2006-2010.

Source: The European health report 2012: charting the way to well-being, World Health Organization 2013, p. 8.

Mean life expectancy may be subject to declines resulting from the periods of failing health due to disabilities and diseases for different age ranges. Despite the fact that European women live averagely 7.5 years longer than men, mean difference in years lived in full health in respect to sex is estimated to be only 5 years.⁹

Broadly speaking, the ageing of population is related to the expanded epidemiological surveillance over infectious diseases at an early stage of life, occurrence of chronic non-infectious diseases later in life and reducing the frequency of premature deaths, which can be attributed to the improvement of living conditions and better access of medical services. Nevertheless, constant efforts to achieve social integration, safety and well-being, as well as availability of medical and social services, according to the

⁹ The European health report 2012: charting the way to well-being, World Health Organization 2013, p. 11.

individual needs of ageing populations of particular countries, should be a priority for decision-makers in the area of health policy.¹⁰

The predicted long-term continuous increase of life span may not happen if economic and social crises correlate with a reduction of expenses for health and other social security benefits, intensification of natural disasters or recurrence of highly pandemic infectious diseases. In order to continue the tendency of prolonging life expectancy we need constant efforts focused mainly on decreasing mortality rates, particularly with regard to cardiovascular, respiratory and infectious diseases, as well as external causes for injuries and poisoning.¹¹

Not only life prolonging actions are taken, but also those oriented towards extending healthy life years without disability. Healthy life years indicator is used for:

- monitoring the state of health which influences productivity and economy
- introducing the concept of life quality
- determining an employment rate among older employees
- monitoring progress in providing access to health care, its quality and stability¹².

An analysis of the healthy life years indicators assessing a mean number of remaining life years without disability for a given person in a defined age demonstrates that this value in Poland is below the mean values for Spain and Denmark. The significance of this factor was recognized in the Lisbon strategy. It is one of the most important structural indicators in Europe. Therefore, it should be expected that the state of health of the elderly in Poland differs considerably from other countries of the EU, e.g. Denmark and Spain. The elderly in Poland fall ill more frequently and have severe difficulties in continuing life roles and taking up new ones – for example roles concerning taking care of relatives with serious neuropathologies (Diagram 3)

¹⁰ The European health report 2012: charting the way to well-being, World Health Organization 2013, p. 3.

¹¹ The European health report 2012: charting the way to well-being, World Health Organization 2013, p. 11.

¹² WHO http://ec.europa.eu/health/indicators/healthy_life_years/index_pl.htm.

Healthy Life Years at birth - Men, from 2004 onwards, time series of 7 years

The 'Healthy Life Years' (HLY) indicator is the expected remaining number of years, lived from a particular age without long-term activity limitation. HLY is compute...

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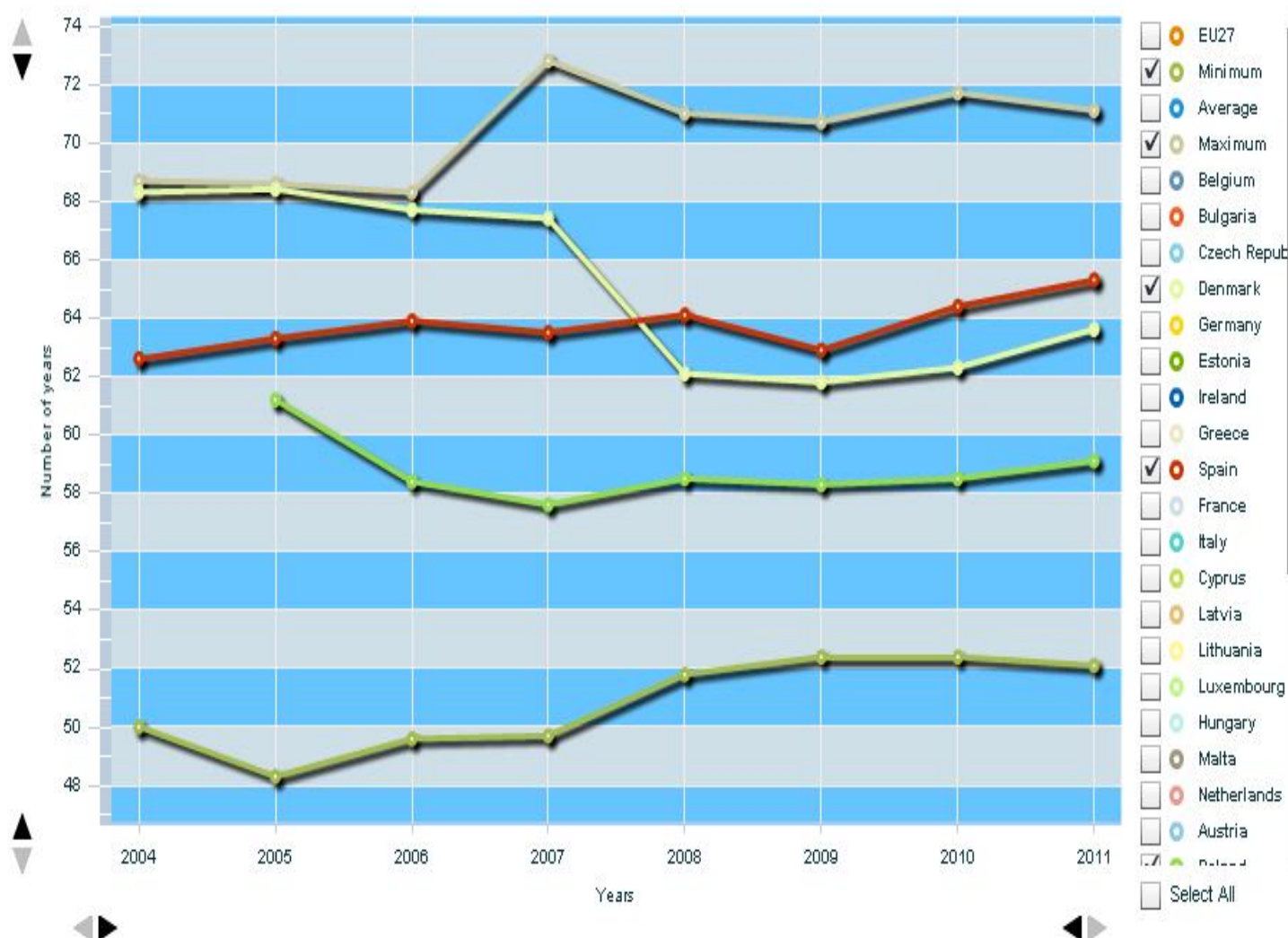


Diagram 3: Healthy life years at birth.

Source: http://ec.europa.eu/health/indicators/healthy_life_years/index_pl.html.

1.3. Demographic processes in Poland

At the end of the year 2010 the total population of Poland stood at 38200 thousand people. The dynamics of changes in population size in the years 2001-2010 was highly diverse with regard to the scale and character of those changes – the mean annual population loss rate equalled 0.14% (from -0.08% in 2006 to +0.09 in 2010).¹³

¹³ Basic Information about Demographic Situation in Poland in 2011, Central Statistical Office 2012, p. 1.

In 2011 a positive population growth was noted. According to estimates, the number of children born exceeded the number of deaths by approximately 15 thousand, which means that, on the average, for every 10 thousand people 4 new persons appeared (in 2010 it was 9 people, at the beginning of 1990s – over 40). Since the 1990s a gradual decrease in the population growth accompanied by the fall in the number of births is observed. The years 2002-2005 mark out the period of population loss which reached its peak in 2003: over 14 thousand fewer children were born in relation to the stated deaths.¹⁴(Diagram 4)

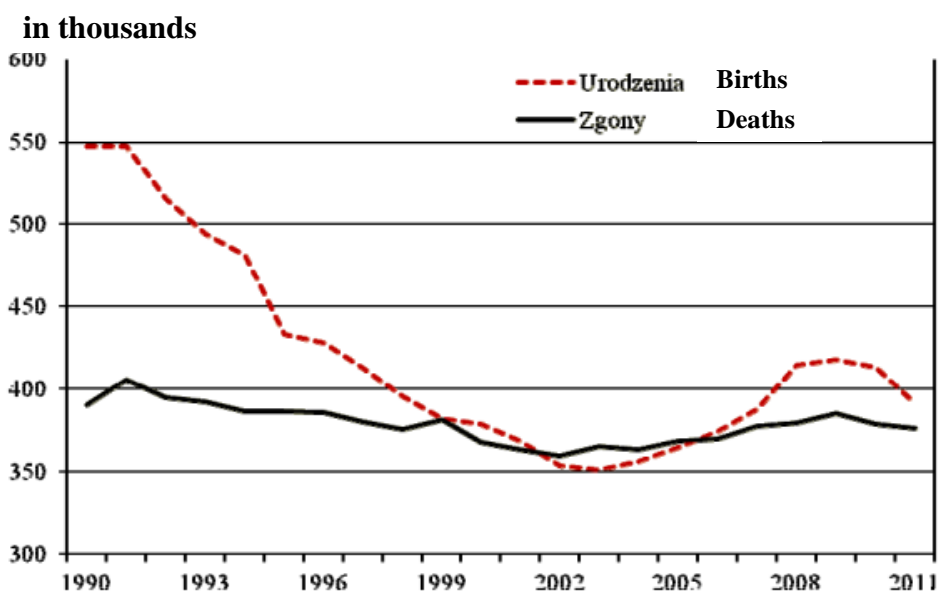


Diagram 4. Natural population movement in Poland in the 1990-2011 period

Source: Basic Information about Demographic Situation in Poland in 2011, Central Statistical Office 2012, p. 1.

In the year 2011 around 391 thousand live births were registered, which constitutes a number over 22 thousand lower than in the previous year. The birth rate run at a level of 10.2‰, i.e. by 0.5 point lower than in the year 2010, whereas 0.3 point higher than at the beginning of this century. In 2004-2009 an increase in the number of births was observed, particularly among the families inhabiting urban environments. Last two years are

¹⁴ Basic Information about Demographic Situation in Poland in 2011, Central Statistical Office 2012, pp. 1-2.

characterized by another drop in the number of births: in 2010 approximately 413 thousand children were born. Birth intensity rate in the rural areas is still higher. In 2010 the rate amounted to 11.4‰, whereas in cities – 10.4‰.¹⁵

Since 1989 Poland has been affected by a so-called birth depression, a low number of births does not guarantee the replacement of generations. In 2010 fertility rate was equal to merely 1.4 point, 0.16 point more than the lowest value in 50 years, registered in 2003. Currently observed fertility rate still runs at a low level. It differs by around 0.75 point from the optimal value which ensures stable economic development.¹⁶

In 2011 around 376 thousand deaths were registered, 2.5 thousand fewer than in 2010, which gave the mortality rate of 9.8‰. Women constituted over 47% of the total number of the deceased. In the years 1992-1998 the mortality rate was systematically decreasing, whereas till 1999 its growth was evident. Approximately 360-380 thousand deaths are registered annually, which shows relatively steady rate of change and stabilization of the mortality rate in Poland. At present the mortality rates for the population of urban and rural areas do not differ considerably, as opposed to the situation in the 1990s and the beginning of the current century. Cardiovascular and neoplastic diseases are the main causes for deaths in Poland, responsible for over 70% of their total number. The next group of causes includes injuries and poisonings – they constitute 6% of the total number of deaths. A high percentage of deaths does not have a defined cause (over 6%). Increased rate of excessive mortality of men is noticeable in Poland. Within younger age groups, starting from the 20-24 years range, the mortality rate for men is observed to be even 4 times higher than for women, whereas in older age groups it is 3 and 2 times higher. The improvement of indicators regarding mortality, which can be noticed since the 1990s, influences beneficially the duration of life in Poland, however, the difference between life duration of women and men is still substantial. In 2010 men lived averagely 72.1 years, and women 80.6 years – 8.5 years longer. In the last 20 years life duration of men increased by almost 6 years and of women by 5.4 years.¹⁷(Diagram 5)

¹⁵ Basic Information about Demographic Situation in Poland in 2011, Central Statistical Office 2012, p. 2.

¹⁶ Basic Information about Demographic Situation in Poland in 2011, Central Statistical Office 2012, pp. 2-3.

¹⁷ Basic Information about Demographic Situation in Poland in 2011, Central Statistical Office 2012, pp. 8-11.

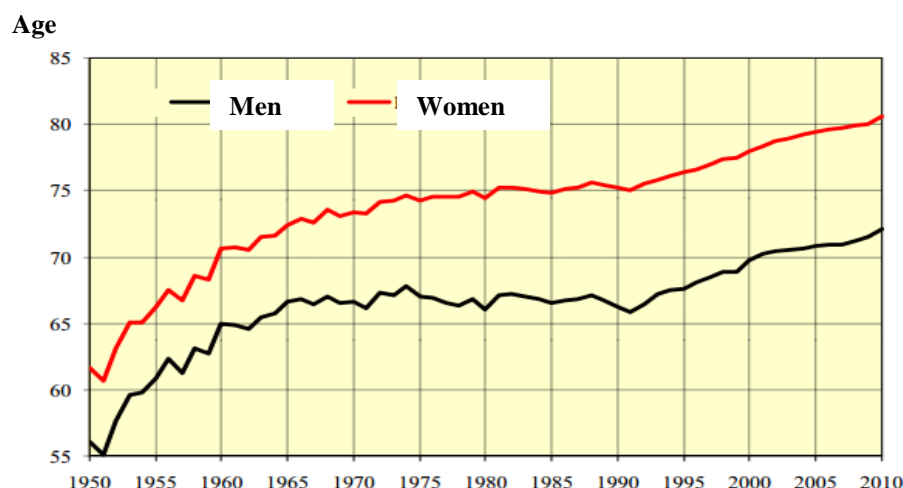


Diagram 5. Mean life expectancy in Poland in the years 1950-2010.

Source: Basic Information about Demographic Situation in Poland in 2011, Central Statistical Office 2012, p. 11.

1.4. Population of Poland in demographic forecasting

As is evidenced in the population transformations witnessed in the past years, the present demographic situation in Poland is more favourable than the situation developed at the turn of the century, but still difficult. Highly unfavourable changes affect the tendencies related to births, which, in the face of massive temporary emigration of the Poles abroad, has adverse influence on the fertility observed in the future. Continually low fertility rates together with a constant increase of life expectancy will eventually lead to the decrease in supply of labour force in the work sector and to the growth of number and percentage of the elderly population, which is a consequence of the advance ageing of the Polish society.¹⁸

Steady increase of population at retirement age will be typical during the changes in the size of population of people at pre-working and working age till 2035. Retirement age in urban areas till 2010 was annually reached by averagely 90-99 thousand people, and the next decade will bring an increase of 1365 thousand. After 2020 the upward

¹⁸ Basic Information about Demographic Situation in Poland in 2011, Central Statistical Office 2012, p. 12.

tendency will be substantially curbed – till 2025 an increase of retirement population will remain at the slightly lower level than that registered among inhabitants of rural areas.¹⁹

Transformations in rural areas, similarly to those observed in the cities, will become more significant after the year 2010. By the end of a forecast horizon around 245 thousand people will reach retirement age, whereas during the subsequent five years the most considerable outflow from the labour market is expected – approximately 345 thousand people. The population of rural areas will change slightly by 2035. The number of people reaching working age will change insignificantly. Within next 5-year periods it should not drop below 240 thousand. To put it briefly, the percentage of people at the age of 60+/65+ will increase in cities by 11.5 pp (in the case of women –13.3), whereas in the rural areas by 9.8 pp. (women – 10.8)²⁰ (Diagram 6).

(in thousands).

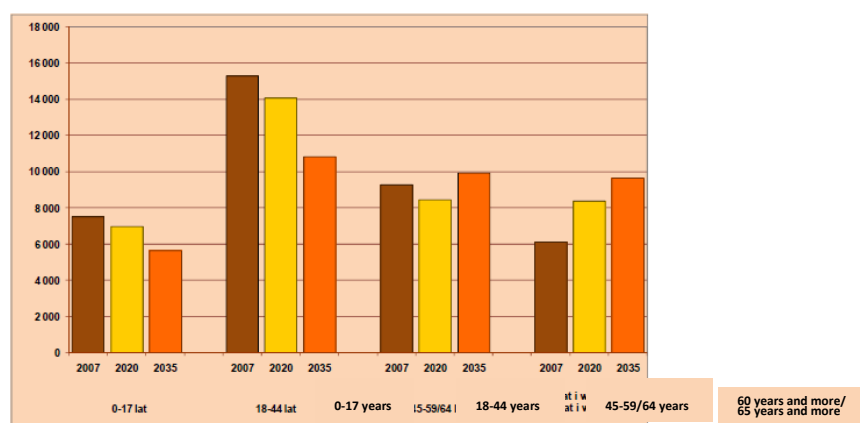


Diagram 6. Population by economic age groups in the years 2007, 2020 and 2035

Source: Population Forecast for the Years 2008-2035, Central Statistical Office, Warsaw 2009, p. 167.

Within the country boundaries during the forecast period a major loss of the population of people at working age is predicted – by 2025 its size will be reduced by 2946 thousand. The most significant loss is expected in the period of 2015-2020 and will amount to 1215 thousand.

¹⁹ Population Forecast for the Years 2008-2035, Central Statistical Office, Warsaw 2009, p. 166.

²⁰ Population Forecast for the Years 2008-2035, Central Statistical Office, Warsaw 2009, p. 167.

It is estimated that by 2035 the population of people at working age will drop by nearly 3806 thousand, and inhabitants of urban areas will comprise almost 87% of the loss.²¹

The progressing ageing of the society will contribute to serious losses in the population of people at mobile age. During the forecast the population will be reduced by 4433 thousand, shifting towards immobile groups of the population. In comparison to the year 2007 the population of people at the age of 45-59/64 will increase by 627 thousand. Transformations within a group at working age in urban and rural areas in the following periods will occur with different intensity in the subsequent periods of the forecast. As a result, the population of people at mobile age is estimated to decrease by 10.7 pp. in the cities and 8.9 pp. in the rural areas. The percentage of the population at immobile age, on the other hand, will grow by 1.7 pp. in the cities and even by 5.6 pp. in the rural areas.²²

In 2008 0-17 age group was equal to 17.7% of the total population inhabiting cities and 22.6% living in the rural areas. Apart from the 2014-2020 period, when a slight increase of the size of the mentioned population was observed, it is evaluated that the constant decline in the size of the group will be evidenced. The most significant losses, amounting to over 100 thousand annually were forecast by 2010, and next after 2025. By 2035 a decrease of over 900 thousand, among both, inhabitants of urban and rural areas, is predicted. To sum up, the percentage of population at the age range of 0-17 years in the population structure according to economic age groups will be reduced by 2.5% in the cities and even 6.4% in the rural areas, which is mainly caused by the birth rate from the period preceding the forecast, as well as assumptions of prognostic nature, such as e.g. standardization of fertility models in urban and rural areas.²³

1.5. Demographic processes in Poznań

On 31.12.2011 the population of Wielkopolska province according to the actual place of residence amounted to 3 455 477 people, 1 680 585 of which are men (48.6%) and 1 774 892 women (51.4%).²⁴

Population age structure in Wielkopolska province presents as follows: the largest percentage of 16.1% constitutes 20-29 age group and 16.0% – 30-39 age group, whereas the smallest percentage of 5.0% constitutes 5-9 age group and 5.2% – 10-14 age group. In

²¹ Population Forecast for the Years 2008-2035, Central Statistical Office, Warsaw 2009, pp. 167-168.

²² Population Forecast for the Years 2008-2035, Central Statistical Office, Warsaw 2009, p. 168.

²³ Population Forecast for the Years 2008-2035, Central Statistical Office, Warsaw 2009, p. 168.

²⁴ Numerical Guide of Health Protection in Wielkopolska Province – 2011, Centre for Public Health in Wielkopolska, Poznań 2012, p. 7.

Wielkopolska province, similarly as in the whole country, a systematic shifts in the population structure according to the economic age groups is being witnessed. In 2011 the population of people at the retirement age grew to 549 231 in a year. The population at the working age was equal to 2 228 465 people. In 2011 in Wielkopolska 38 082 live births were registered. In 2010 the number of live births was 40 909 children.²⁵

In 2011 30 755 deaths were noted, 17 456 of which in the cities and 13 299 in rural areas. In 2010 31 037 deaths were registered. Population growth in 2011 amounted to 7 327 people. The population growth rate as per 1000 people was 2.12%. In 2011 the negative population growth was registered in the city of Kalisz and Koło district.²⁶

The average life duration of men was 72.9 years, whereas of women 80.9 years, which does not differ considerably from the national average.²⁷

Table. 1. Population of the province and city of Poznań by age groups.

age	Wielkopolska			m. Poznań		
	2009	2010	2011	2009	2010	2011
Ogółem	3 408 281	3 419 426	3 455 477	554 221	551 627	553 564
z tego :						
0-4	191 203	196 885	202 526	27 226	27 883	28 856
5-9	169 162	169 284	173 680	20 849	21 017	22 038
10-14	188 684	183 728	180 147	21 126	20 648	20 242
15-19	232 865	222 513	212 851	27 800	26 046	23 864
20-29	573 171	564 363	557 126	95 390	90 220	95 223
30-39	523 430	538 263	551 897	95 348	99 528	93 602
40-49	425 990	422 076	427 253	61 306	60 594	60 730
50-59	501 092	498 171	498 071	84 964	82 143	80 948
60-69	305 766	324 651	348 509	58 535	61 580	66 145
70 lat	296 918	299 492	303 417	61 677	61 968	61 916
i więcej						

Source: Numerical Guide of Health Protection in Wielkopolska Province - 2011, Centre for Public Health in Wielkopolska, Poznań 2012, p. 12.

²⁵ Numerical Guide of Health Protection in Wielkopolska Province – 2011, Centre for Public Health in Wielkopolska, Poznań 2012, p. 7.

²⁶ Numerical Guide of Health Protection in Wielkopolska Province - 2011, Centre for Public Health in Wielkopolska, Poznań 2012, p. 7.

²⁷ Numerical Guide of Health Protection in Wielkopolska Province - 2011, Centre for Public Health in Wielkopolska, Poznań 2012, p. 7.

Table 2. Poznań population by age groups (in thousands)

period	pre-working (0-17 years)	working (18-59/64 years)	retirement (above 59/64 years)
2000	100.4	369.6	93.6
2002	111.7	382.9	93.8
2001	106.3	371.8	93.8
2003	96.2	384.0	94.0
2004	92.7	383.8	94.3
2005	90.2	382.8	94.9
2006	88.2	379.4	97.3
2007	86.4	375.0	99.5
2008	85.1	370.1	101.5
2009	84.5	366.2	103.5
2010	83.9	362.1	106.0

Source: UMM webpage.

<http://www.poznan.pl/mim/s8a/charts.html?co=print&id=7&instance=1009&parent=264&lang=pl>, entry date 1.05.2013r.

The population of Poznań, as of the majority of big cities in Poland, was systematically reduced over the recent years. The largest population in Poznań, amounting to 590.1 thousand people, was registered in 1990. At the end of 2010 Poznań was inhabited by 551.6 thousand people, which means that in 20 years the city population shrank by 38.5 thousand, i.e. 6.5%. A decrease in the population density in Poznań is an indirect result of a population loss. In 2010 per every 1km² there were 2107 people. In spite of the unfavourable trends, Poznań was still holding the fifth position in the size of population among Polish cities.²⁸

Structure by sex and age

²⁸ Sytuacja demograficzna na tle aglomeracji poznańskiej oraz największych miast w 2010 r. (Demographic situation of Poznań agglomeration and largest cities in 2010), p. 7.

The age structure of Poznań inhabitants is subject to dynamic changes. Since 1990, due to a small number of births, the population at pre-working age (0-17 years) decreased by 44.8%. The population of the group at working age increased by 2.1% (18-54/64 years), which was caused by a population boom at the turn of the 70s and 80s taken in by this age range. However, since 2005 the percentage of population at working age has been shrinking (in comparison to 2010 – by 1.8 pp).²⁹

The most significant growth in comparison to 1990 was noted in the case of population at retirement age (by 26.5%), which was convergent with the European-wide tendency of society ageing. The process accelerated considerably after 2005 – in 5 years the value reached 2.4 pp. In 2010 a subpopulation at working age counted 362,1 thousand residents (65.6%), 2/3 of which (232.0 thousand) belonged to the mobile group (18-44 years). The number of people at retirement age (105.6 thousand) began to exceed more and more significantly the size of the pre-working group (83.9 thousand). Per every 1000 people at working age there were 523 inhabitants at non-working age.³⁰

Due to the fast decrease in the number of births in the 1990s, the population of the youngest people was subject to a particularly rapid reduction in this period. Taking the year 1990 as a baseline, in the groups of:

- 0-2 years (nursery age) – the loss was equal to 10.2% (up to 17.8 thousand people in 2010),
- 3-6 years (kindergarten age) – the population shrank to 42% (up to 19.2 thousand in 2010),
- 7-12 years (primary school age) – the loss was 66% (up to 24.2 thousand),
- 13-15 years (middle school age) – the decrease in population by 53% (up to 12.9 thousand),
- 16-18 years (secondary school age) – the loss was equal to 40% (up to 15.3 thousand people in 2010)³¹

²⁹ Demographic situation of Poznań agglomeration and largest cities in 2010, p. 7.

³⁰ Demographic situation of Poznań agglomeration and largest cities in 2010, p. 7.

³¹ Demographic situation of Poznań agglomeration and largest cities in 2010, p. 7.

Nevertheless, because of the gradual increase in the number of births registered since 2002, first the group of 0-2 years began to grow (by 30% in the years 2002-2010), and then, since 2005, also the group at the age of 3-6 years (by 10%). Within the next years the population of children at the primary school age will expand. Such tendencies indicate the necessity to increase the capacity of nurseries and kindergartens.³²

People at higher education age (19-24 years) at the beginning of the twenty-first century constituted a climax of population boom, reaching a record number in 2002 (73.9 thousand), higher by 41% in relation to 1990. In 2010 the population of people at the age of 19-24 years comprised only 44.6 thousand, i.e. 40% fewer than 8 years earlier (5.8% less than a year before). Such fast decrease in the population of young people at higher education age (also in the region and in the country) is directly reflected in the problems with the enrolment for some majors at higher education institutions in Poznań.³³

At the end of 2010 the largest population was formed by groups at the age of 30-34 years, and the second largest populations by the groups of 25-29 years, 35-39 years and 55-64 years. They consist of generations which belong to two consecutive population booms. Men outnumbered women in generations aged up to 24 years. The numerical superiority of women at the age range of 25-34 years was caused by a larger inflow of women remaining in cities immediately after graduating from higher education institutions. Additionally, the numerical superiority of women, increasing in older generations, was conditioned biologically. In comparison to 1990 the feminization rate was increasing steadily, however, since 2000 the number of women per every 100 men did not change and amounted to 115.³⁴

The ageing of Poznań residents is a serious problem which will accelerate over the next years. It will be evident, on the one hand, in the increasing average age of the population, on the other hand, in the growth of the population of people at the advanced age. Currently the median age of Poznań inhabitants is 38.7 years, whereas 5 years earlier it was lower by one year, and at the beginning of 1990s it assumed the value slightly exceeding 34 years. Demographic senescence rate, defining the percentage of people at the age of 65 years and more amounts to 14.9% (in 2000 – 13.6%), while the percentage of inhabitants in the oldest age ranges (80 years and more) equals to 4.1% and is 1.7 pp higher than a decade before. Women predominate significantly among elderly people and

³² Demographic situation of Poznań agglomeration and largest cities in 2010, pp. 7-8.

³³ Demographic situation of Poznań agglomeration and largest cities in 2010, pp. 7.-8.

³⁴ Demographic situation of Poznań agglomeration and largest cities in 2010, p. 8.

their number at the age of 80 years and more is over two times higher than that of men. Due to the changes in the age structure there are more and more people aged 65 years and more per the youngest generation of Poznań inhabitants, i.e. people aged up to 14 years (in 2010 there were 1185 elderly inhabitants per every 1000 children and young people up to 14 years, in 2000 this value equalled to 924).³⁵

Natural population movement

Recent years have brought a low level of mortality. While 20 years ago 7 thousand deaths were registered, currently their number has stabilized at the level of around 5.5 thousand. It means that per every 1000 inhabitants around 10 people die annually, i.e. statistically nearly 2 fewer than in 1990. This situation is caused by a constant improvement of conditions of increasing average life duration. They include: more diversified, healthier diet, growing number of people quitting smoking and improvement of health care quality. The last aforementioned condition is also a reason for considerable decrease in infant mortality. At present one in approximately 200 infants (4.8‰) die in the first year of living, while no later than 20 years ago it was one in 60 (16.4‰). Similar situation occurs in the remaining large cities in Poland.³⁶

Two in five deaths in Poznań are caused by diseases related to circulatory system, whereas one in four deaths is attributed to neoplastic diseases. Other disorders contribute to deaths considerably less frequently – the diseases of digestive system cause one in nineteen deaths, and respiratory diseases – one in 24 deaths. Generally speaking, 2/3 of deaths are registered in the group of 70 and more years. It is simultaneously the only age range where the number of women's deaths outnumbers those of men's. This situation is caused by a constant improvement of conditions of increasing average life duration. They include: more diversified, healthier diet, growing number of people quitting smoking and improvement of health care quality. The last aforementioned condition is also a reason for considerable decrease in infant mortality. At present one in approximately 200 infants (4.8‰) die in the first year of living, while no later than 20 years ago it was one in 60 (16.4‰). Similar situation occurs in the remaining large cities in Poland.³⁷

³⁵ Demographic situation of Poznań agglomeration and largest cities in 2010, pp. 8-9.

³⁶ Demographic situation of Poznań agglomeration and largest cities in 2010, pp. 8-9.

³⁷ Demographic situation of Poznań agglomeration and largest cities in 2010, pp. 9-10.

In 2010 6045 children were born, which means that for the first time in 7 years the number of births was lower than a year before (6176). The number of births (11.1 per 1000 inhabitants) was higher than the number of deaths (10.4‰), which resulted in maintaining a positive population growth amounting to 0.8‰ in comparison to 1.2‰ in 2009.³⁸

Life expectancy

In 2010 an estimated average life expectancy for people born in that year equalled for boys 73.8 years, and for girls – 80.6 years. To compare, 60 year old people statistically will live 18.8 years (men) or 23.8 years (women)³⁹ (Diagram 7).

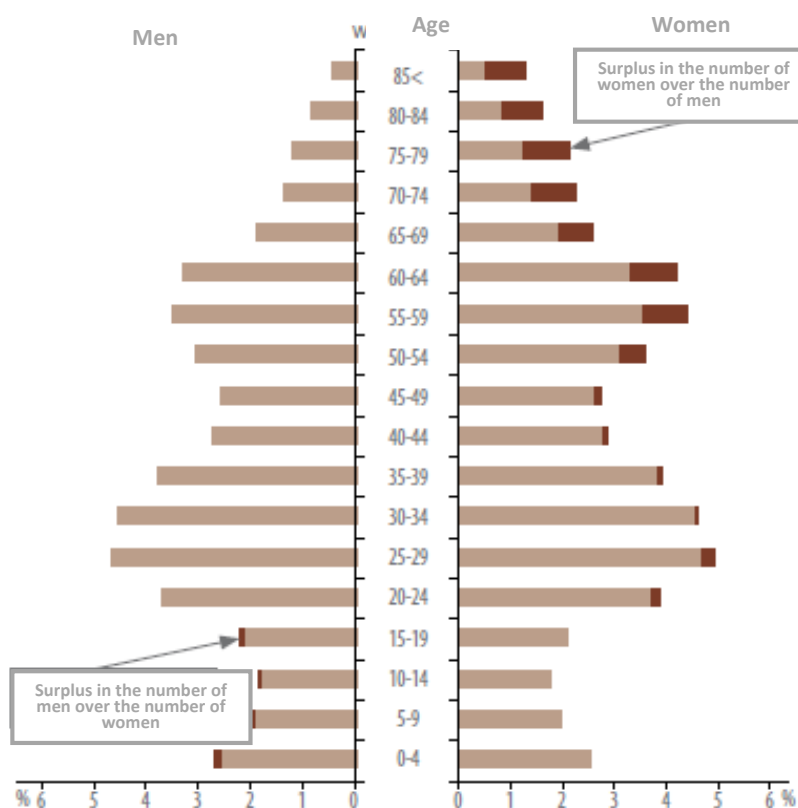


Diagram 7. Population structure in Poznań by sex and age in 2011.

Source: Facts and numbers, Department of City Development in Poznań City Hall, Poznań 2012, p. 4.

Since 2006 in Poznań a positive population growth has been registered and it is caused mainly by an increase in the number of births. In December of 2011 it amounted

³⁸ Demographic situation of Poznań agglomeration and largest cities in 2010, pp. 9-10.

³⁹ Demographic situation of Poznań agglomeration and largest cities in 2010, p. 10.

to 0.8‰. The only factor causing a decrease of inhabitants population is a migration loss, in 2011 reaching the level of -4.5‰⁴⁰ (Diagram 8).

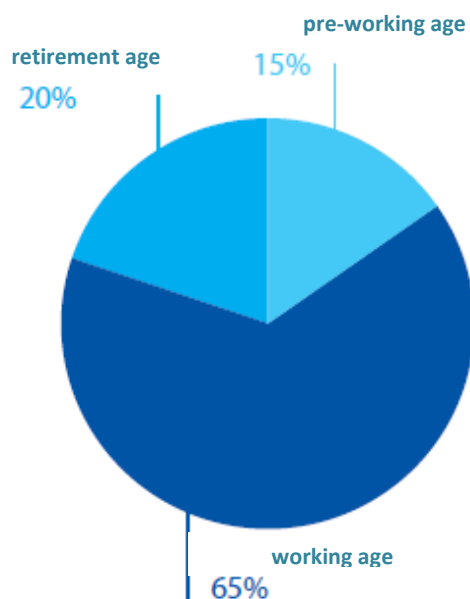


Diagram 8. Population structure in Poznań by economic age groups.

Source: Report on City Condition, Poznań City Hall, Poznań 2011, p. 13.

Poznań. Facts and numbers, Department of City Development in Poznań City Hall, Poznań 2012, p. 4.

1.6. Population of Poznań in demographic forecasting.

In a demographic forecast of Central Statistical Office for the city of Poznań a gradual population decrease, characteristic also for the majority of large cities in Poland, is predicted. By 2035 the size of population will shrink by around 490 thousand people, i.e. by over 11%. The loss in the number of people will refer to pre-working (the period of increase in the years 2010-2021 will be followed by a drop of 16%) and working age – 19%. In turn, a significant growth (by nearly 20%) of the group representing working age

⁴⁰ Social and Economic Situation, Statistics, Analysis and Reporting Unit in the Department of City Development, Poznań 2012, p. 14.

will be observed. The population which exceeded 65 years will grow by 32%, 85 years – by 87%.⁴¹

It is estimated that during the forecast period there will occur temporary increases in the population at pre-working age: children and youth aged 3-6 years by 2015, 7-12 years by 2021, 13-15 years in 2016-2025, 16-18 years in 2019-2028 and 19-24 years in 2023-2033.⁴²

In every year of the 2011-2035 period a negative population growth is predicted and it will be caused by a decrease in the number of births (by 33%) and a slight rise in the number of deaths – by 1.5%. Therefore, a negative population growth will be subject to an increase from the level of -422 people registered in 2011 to -2444 people in 2035.⁴³

Within the district of Poznań the opposite situation will develop: by 2035 the size of population will expand nearly by half, i.e. 153 thousand people, reaching the value of 480 thousand people. As a result, by 2035 the community living within the boundaries of Poznań agglomeration will grow by around 10%, amounting to 970 thousand people. In the district and agglomeration of Poznań an increase of the population of all economic age groups will be witnessed, however, the significant growth will concern only the group at working age. In 2035 the population at the age of 65 years and more in Poznań district will increase by 273%, above 85 years – by 207%. An increase in other groups will be hardly evident. In 2035 the number of births in Poznań province will approximate the number registered in 2011, but the number of deaths will grow significantly, i.e. by 66%.⁴⁴

For the years 2030 the first negative population growth is predicted (at the level of -32 people), and it will not change by the end of the forecast horizon (-208 people). In 2035 the population of Poznań agglomeration at the age of 65 years and more will grow by 83% (86.5 thousand), above 85 years by 115% (14.2% thousand). The number of births will decline by 22%, whereas the number of deaths will increase by 36%. Consequently,

⁴¹ Demographic forecast up to 2035. The city and the district of Poznań, GEOPOZ Institute for Surevying and Municipal Cadastre, available online:

http://www.city.poznan.pl/mapa_geopoz/data/analizy/prognozy_demograficzne/indeks.php.

⁴² Demographic forecast up to 2035. The city and the district of Poznań, GEOPOZ Institute for Surevying and Municipal Cadastre, available online:

http://www.city.poznan.pl/mapa_geopoz/data/analizy/prognozy_demograficzne/indeks.php.

⁴³ Demographic forecast up to 2035. The city and the district of Poznań, GEOPOZ Institute for Surevying and Municipal Cadastre, available online:

http://www.city.poznan.pl/mapa_geopoz/data/analizy/prognozy_demograficzne/indeks.php.

⁴⁴ Demographic forecast up to 2035. The city and the district of Poznań, GEOPOZ Institute for Surevying and Municipal Cadastre, available online:

http://www.city.poznan.pl/mapa_geopoz/data/analizy/prognozy_demograficzne/indeks.php.

in 2019 the negative population growth will occur for the first time (-67 people), and it will systematically grow up to -2652 people in 2035⁴⁵ (Table 3).

Table 3. Average life expectancy in Wielkopolska province in comparison to the whole country

			2005	2006	2007	2008	2009	2010	2011	
60	years	Poland	men	17,5	17,7	17,7	17,9	17,9	18,3	18,5
			women	22,7	22,8	22,9	23,1	23,2	23,5	23,8
		Wielkopolska	men	17,6	17,4	17,7	17,9	18	18,1	18,4
			women	22,5	22,6	22,6	22,9	23	23,2	23,6
65	years	Poland	men	14,4	14,5	14,6	14,7	14,7	15,1	15,3
			women	18,6	18,8	18,9	19,0	19,1	19,4	19,7
		Wielkopolska	men	14,4	14,2	14,5	14,7	14,7	14,8	15,1
			women	18,4	18,5	18,6	18,8	18,9	19,1	19,5

Source: Numerical Guide of Health Protection in Wielkopolska Province - 2011, Centre for Public Health in Wielkopolska, Poznań 2012, p. 21.

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⁴⁵ Demographic forecast up to 2035. The city and the district of Poznań, GEOPOZ Institute for Surevying and Municipal Cadastre, available online:
http://www.city.poznan.pl/mapa_geopoz/data/analizy/prognozy_demograficzne/index.php.

Pomyślne starzenie się w perspektywie nauk społecznych i humanistycznych, (Successful Ageing in the Perspective of Social Sciences and Humanities), joint publication edited by J. T Kowaleski i T. Szukalski, Łódź 2008.

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6. Poznań 2012. Raport o stanie miasta, Urząd Miasta Poznania (Report on City Condition, Poznań City Hall), Poznań 2011.
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8. Prognoza demograficzna do 2035 roku. Poznań i powiat poznański, Zarząd Geodezji i Katastru Miejskiego GEOPOZ, dostępna online, (Demographic forecast up to 2035. The city and the district of Poznań, GEOPOZ Institute for Surevying and Municipal Cadastre), available online: http://www.city.poznan.pl/mapa_geopoz/data/analizy/prognozy_demograficzne/index.php.
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2. Introduction to dementia

2.1. Ageing and neurodegenerative diseases

The problem of ageing of European societies is one of the major social and economic challenges of the twenty-first century. It will afflict all of the EU countries and affect most areas of politics.

By **2025** over **20 % of Europeans will reach 65 years or more**, and, at the same time, the number of people over 80 years old will increase rapidly.

Since elderly people require different kind of medical care, health systems will have to be adapted in order to comply with the needs of this age group and maintain their financial stability⁴⁶.

Dialogue concerning this matter is carried out not only on the scientific level, but also on the level of society, being reflected, for example, in public media. Problem related to the growing number of geriatric populations lies in the rising percentage of elderly people, who were diagnosed with cognitive impairment. Alarming reports and forecasts about the growing number of both: populations of elderly people and people with dementia, call to take actions in order to protect the sector providing care for the indicated population. The need for action is clearly expressed by World Health Organization⁴⁷,

⁴⁶ http://ec.europa.eu/health/ageing/policy/index_pl.html

⁴⁷ WHO, AS, Dementia - A public health priority

http://www.who.int/mental_health/publications/dementia_report_2012/en/, data wejścia 2.05.2013r.

Alzheimer Association ⁴⁸, and other experts. ^{49, 50} It is worth noting that currently the problem of society ageing is, as a matter of fact, inextricable from cognitive impairments and should be considered jointly and comprehensively⁵¹.

Due to disturbing facts, in Europe, as well as in other parts of the world, numerous reports concerning the means of providing care for the elderly are being published. ^{52,53} For many years programmes oriented towards securing this sector of health care have been designed, yet Poland still lacks an integrated system, programmes, trainings and courses focused on the problems connected with cognitive impairments. In recent years scientific researches have been undertaken, however, it seems to be an insufficient action in view of

⁴⁸ Official website Alzheimer Association http://www.alz.org/about_us_strategic_plan.asp, data wejścia 25.04.2013r.

⁴⁹ Szatur-Jaworska B., Ageing of Polish Population – Challenges for Social Politics. *Gerontol. Pol.* 2002; 10, 4: 199-206.

⁵⁰ Bryła M., Manicka-Bryła I., Process of Population Ageing as a Challenge for Health Policy. *Gerontol. Pol.* 2011; 19, 1: 40-46

⁵¹ Michalak S. Dementia as a Medical and Social Problem. *Family Medicine & Primary Care Review* 2005m 7, 3: 708-710.

⁵² Szczerbińska K. Kurs Organization of Care of Elderly People in Poland and Europe. Educational programme of the College of Family Physicians in Poland
<http://www.docedu.klrwp.pl/print.php?id=135> date of access: 22 April 2013 3pm

⁵³ Durda M. Organization of Care of Dementia Patients in Poland in Comparison to the Developing and Developed Countries. *Gerontol. Pol.* 2010; 18, 2: 76-85.

such an enormous problem ^{54 55 56 57 58}
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Among mental diseases and disorders afflicting more and more ageing populations of industrialized societies, including Poland, a real challenge – not only for researchers – is posed by dementia-type diseases, with Alzheimer type dementia as the most frequently occurring.

Dementia poses a major medical, social and economic problem in developed countries. An increasing life expectancy, and as a result, an increasing number of people suffering from geriatric diseases, requires medical and non-medical care, plenty of efforts and resources, and still the effects may appear insignificant. Dementia is not a disease but a group of clinical symptoms which may have many causes, and in some cases, when properly diagnosed and treated, they may be suppressed. For that reason, each time the symptoms of dementia are suspected, apart from confirming a diagnosis, its original causes should be identified. Some of the diseases that can cause symptoms of dementia are Alzheimer's disease, vascular dementia, Lewy body dementia, frontotemporal dementia, Huntington's disease, and Creutzfeldt-Jakob disease. Doctors have identified other conditions that can cause dementia or dementia-like symptoms including reactions to medications, metabolic problems and endocrine abnormalities, nutritional deficiencies, infections, poisoning, brain tumours, anoxia or hypoxia (conditions in which the brain's oxygen supply is either reduced or cut off entirely), and heart and lung problems. Although

⁵⁴ NATIONAL PROGRAMME FOR STUDY OF BRAIN DISEASES CAUSING DEMENTIA Project on the initiative of the Polish Alzheimer Society programme project prepared by Prof. Maria Barcikowska, Prof. Jacek Kuźnicki and Prof. Andrzej Szczudlik (December 2010).

⁵⁵ Roszkowska H. Selected Elements of Health Situation of Elderly People in Poland in Comparison to the Candidate Countries to the European Union and Member States. *Gerontol. Pol.* 2003; 2, 2: 63-71.

⁵⁶ Marcinowicz L., Zajkowska E., Home Care in the United States *Gerontol. Pol.* 2003; 2, 3: 121-124.

⁵⁷ Ryś L., Szczerbińska K., Franco A., "Alzheimer Plan" – French Project for Care of Dementia Patients. *Gerontol. Pol.* 2004; 12, 1: 11-15.

⁵⁸ COMMUNICATION FROM THE COMMISSION TO THE EUROPEAN PARLIAMENT AND COUNCIL on an European initiative on Alzheimer's disease and other dementias http://ec.europa.eu/health/archive/ph_information/dissemination/documents/com2009_380_pl.pdf, data wejścia 15.04.2013r.

it is common in very elderly individuals, dementia is not a normal part of the ageing process⁵⁹. The dementia itself also requires a diagnosis and ability to distinguish it from, for example, natural ageing processes⁶⁰.

According to The ICD-10 Classification of Diseases and Health Related Problems published by World Health Organization dementia is a set of syndromes caused by a brain disease, generally of chronic or progressing nature, which is characterised by a disorder of higher cortex functions, such as: memory, ability to think, understand and learn, counting, orientation, language functions and ability to assess⁶¹.

Doctors diagnose dementia only if two or more brain functions - such as memory and language skills are significantly impaired without loss of consciousness.

More than 600 disorders afflict the nervous system. Neurodegenerative diseases are defined as hereditary and sporadic conditions which are characterized by progressive nervous system dysfunction. These disorders are often associated with atrophy of the affected central or peripheral structures of the nervous system. They include diseases such as Alzheimer's disease and other dementias, brain cancer, degenerative nerve diseases, encephalitis, epilepsy, genetic brain disorders, head and brain malformations, hydrocephalus, stroke, Parkinson's disease, multiple sclerosis, amyotrophic lateral sclerosis (ALS or Lou Gehrig's disease), Huntington's disease, Prion diseases, and others. Many disorders can cause dementia. Some, such as Alzheimer's disease or Huntington's disease, lead to a progressive loss of mental functions and disability. But other types of dementia can be halted or reversed with appropriate treatment. People with moderate or advanced dementia typically need round-the-clock care and supervision to prevent them from harming themselves or others. They also may need assistance with daily activities such as eating, bathing, and dressing⁶⁸.

The framework of health information on neurodegenerative diseases sometimes includes brain diseases, defined as pathologic conditions also affecting the brain (composed of the intracranial components of the central nervous system). This includes (but is not limited

⁵⁹ <http://www.ninds.nih.gov/disorders/dementias/dementia.htm>

⁶⁰ *ibidem*

⁶¹ The ICD-10 Classification of Mental and Behavioural Disorders. Diagnostic criteria for research, World Health Organization, Geneva 1993.

to) the cerebral cortex; intracranial white matter, basal ganglia, thalamus, hypothalamus, brain stem, and cerebellum (MeSH definition) ⁶².

Late – life dementia is an umbrella term, which is used to describe late – onset diseases characterized by progressive cognitive – behavioral decline and inability to live independently ⁶³, ⁶⁴, ⁶⁵. Late – onset dementias, which include: Alzheimer’s disease (Alzheimer disease; AD), Vascular dementia (VaD), Lewy body dementia (LBD; DLB), and Mixed dementia result from irreversible neurodegenerative changes in affected areas of the brain. These clinical syndromes can be described by the type of symptoms; order at which symptoms emerge over time and dynamics of cognitive deterioration. The precise diagnosis of the cause of dementia can only be made by post – mortem brain biopsy ⁶⁶.

Moreover, dementia costs affect not only individuals and their families but also local communities and national governments. It is estimated that the global economic burden of dementia is US\$315 billion in 2005 to US\$422 billion in 2009, and will increase⁶⁷: Furthermore, this increase of 34% will more than double to 85% in 2030⁶⁸. Interestingly, about 70% of the global societal costs of dementia occur in just two WHO Global Burden of Disease (GBD) regions: western Europe and North America. And while the minority (46%) of people with dementia live in HIC, 89% of total costs of dementia are incurred in those countries ⁶⁹. It is due to the fact that in LIC the formal social care sector practically does not exist. Thus, responsibility for providing care PWD falls on unpaid informal caregivers. Nevertheless, rapid social, political and economic transformations of those countries, including demographic ageing, increased mobility of people, modernization, transformation of traditional family and kinship structure, education of women and their participation in the workforce and declining fertility threaten informal care system in those regions.

⁶² http://ec.europa.eu/health/major_chronic_diseases/diseases/brain_neurological/index_en.html.

⁶³ Lee L, Weston WW, Heckman G, Gagnon M, Lee FJ, Sloka S. Structured approach to patients with memory difficulties in clinical practice. *Can Fam Physician*. 2013; 59: 249 – 254.

⁶⁴ Lee AY. Vascular dementia. *Chonnam Med J*. 2011;47:66-71.

⁶⁵ Alzheimer’s disease. Unraveling the mystery. National Institute of Ageing, 2008. U.S. Department of Health and Human Services, 2008. Publication Number: 08-3782

⁶⁶ Józwiak A. Dementia in the elderly. *Geriatrics* 2008;2:237–246.

⁶⁷ Wimo et al 2013.

⁶⁸ *ibidem*

⁶⁹ *ibidem*

2.2 Epidemiology of dementia

More recent estimates say that the number of people with dementia will double every 20 years from 24.3 million in 2005 to reach 81.1 million in 2040 ^{70, 71, 72}. From that number 60% of dementia patients live in low- and middle-income countries ^{71,72}. And while in high income countries many people with dementia live in health and social care facilities in low income countries (LIC) they are provided with more informal care. For that reason it is important to note that while the number of dementia patient continues to rise, at the same time the number of required professional care is not expected to rise ⁷³. For that reason dementia patients are increasingly dependent of informal care provided by their family members, especially spouses, children, children-in-law, other relatives and friends, mostly females ^{74, 75, 76, 77, 78, 79}. Another problem is that there are not enough places in nursing homes and for that reason most dementia subjects are cared for in their own homes. Consequently, as majority of persons with dementia (PWD) are cared at home by family members dementia is often called a ‘family disease’⁸⁰ as it creates two victims: the patient and the caregiver. As for the patient along with time his or her physical, mental and cognitive abilities deteriorate. At the same time, with the progression of disease

⁷⁰ Bruvik et al 2012;

⁷¹ Prince et al 2013.

⁷² Wimo et al 2013.

⁷³ Zwaanswijk et al 2013.

⁷⁴ Balducci et al 2008.

⁷⁵ Brodaty and Donkin 2009.

⁷⁶ Conde-Sala et al 2010;

⁷⁷ Connell et al 2001.

⁷⁸ Nguyen 2009.

⁷⁹ Papastavrou et al 2007.

⁸⁰ Dang at al. 2008.

caregiving becomes more complex, stressful and demanding. For that reason caregiver are often called ‘the invisible patients’^{81, 82}.

According to epidemiological estimates, currently there are 35.6 million individuals suffering from dementia worldwide. Individuals with dementia represent approximately 5 – 7% of all world population of older adults above age 65. To add, age – specific, gender – specific and regional differences in occurrence of dementia can be observed. The percentage of persons affected by dementia, which amounts to 3-5 % in the 65 – 69 age group increases with age to reach approximately 35 – 40% in the oldest old (those aged 90 and above). Furthermore, females, especially older ones, develop dementia more often than males. This phenomenon is prominent (but not statistically significant) in Western Europe, where considerable differences between females and males can be observed across all age groups. Also, regional differences in prevalence of dementia can be found. It is the least frequent in Sub – Saharan region of Africa (2.07%), in East Asia (4.19%) and high – income countries of Asia –Pacific region (5.57%) and most frequent in Latin American countries (8.5%). In contrast, the mean prevalence of dementia in Western Europe amounts to 6.92%.

Additionally, prognostic data show that due to increasing longevity and growing proportion of elderly people in the entire population the number of individuals with dementia will have risen to 66 million by the year 2030 and to >130.4 million by the year 2050.

Differences in occurrence between different subtypes of dementia can also be found. Late – onset Alzheimer’s disease is considered the most common form of dementia in the elderly. Nowadays individuals with AD account for approximately 50% - 75% of all cases of dementia in the world and affects approximately 3.9% of the world population. As with all dementias, age – specific differences in prevalence of Alzheimer’s disease can be observed so the occurrence of AD goes up across age pyramid. Epidemiological analyses point out that the chance of developing the disease doubles every five years to reach 45% in the population of persons aged ≥ 85 . Moreover, the pattern of gender – specific and regional variations in occurrence of AD is similar to those observed in all dementias. Current epidemiological findings indicate that in the United States, for

⁸¹ Balducci et al 2008.

⁸² Brodaty and Donkin 2009.

instance, there are as many as 5.2 million individuals living with the disease, who make one – tenth of all Americans over 65 years of age. As far as gender is concerned, there are considerable differences in incidence rates, which show that females seem to be at higher risk of developing dementia than males (13.6 and 16.9 per 1,000 person – years for U.S. females and males respectively). Epidemiological prognoses indicate that due to population ageing the number of individuals afflicted by AD will have reached >115 million by the year 2050.

Vascular dementia (VaD), which remains the second most frequent form of dementia may occur in up to 6 – 10% of all persons above 65 years of age and accounts for approximately 20 – 40 % of all dementias [0,0] whereas Lewy body dementia (DLB) may be found in up to 10 – 30% cases of dementia, depending on classification criteria and methodology. A number of VaD or LBD patients manifest overlapping symptoms of Alzheimer’s disease (mixed dementia). To add, patterns of gender – specific and regional variations in occurrence of VaD and LBD can be indicated that are similar to those generally observed in all dementias. Furthermore, differences in occurrence of VaD between various ethnic groups living in the same area may also be seen. For example, the analyses have shown that African Americans living in the U.S. were twice as likely to develop VaD as Americans of Caucasian descent. VaD was also common in Asian American males.

Western Europe is the GBD region with the highest number of people with dementia (7.0 million), closely followed by East Asia (5.5 million), South Asia (4.5 million) and North America (4.4 million). Nine countries with the highest number of people with dementia in 2010 (million or more) include China (5.4 million), the USA (3.9 million), India (3.7 million), Japan (2.5 million), Germany (1.5 million), Russia (1.2 million), France (1.1 million), Italy (1.1 million) and Brazil (1.0 million)⁸³. (Table 4).

Table 4. The occurrence of dementia in Western Europe in different age groups by gender.

⁸³ Dementia: a Public Health Priority, World Health Organization & Alzheimer’s disease International, s. 13.

GBD region	Sex	Age group (years)							Standardised prevalence*, for those aged 60 and over
		60–64	65–69	70–74	75–79	80–84	85–89	90+	
EUROPE									
Europe, Western	M	1.4	2.3	3.7	6.3	10.6	17.4	33.4	7.29*
	F	1.9	3.0	5.0	8.6	14.8	24.7	48.3	
	All	1.6	2.6	4.3	7.4	12.9	21.7	43.1	6.92

Source: Dementia: a public health priority, World Health Organization 2012, p. 14.

Table 5. The occurrence of dementia in Central and Eastern Europe in the relevant age groups.

GBD region	Age group (years)						Age-standardised prevalence for all those aged 60 years and over
	60–64	65–69	70–74	75–79	80–84	85+	
EUROPE							
Europe, Central	0.9	1.3	3.3	5.8	12.2	24.7	5.78
Europe, Eastern	0.9	1.3	3.2	5.8	11.8	24.5	5.70

Source: Dementia: a public health priority, World Health Organization 2012, p.15.

Dementia in Poznan

First of all, these are the tips provided in outpatient conditions and home for primary and secondary health care on the prevalence and incidence divided into adults and children and young people, as well as hospital morbidity and indicators of the causes of death. The presented data on the prevalence of hospital include the underlying disease, the doctor recognized as the main cause of hospitalization according to ICD-10. Figures do not include the comorbidities that are also the subject of medical treatment, but do not constitute the main cause of hospitalization. Hospital morbidity refers only to the patients of nonpsychiatric wards of all specialties and each person undergoing stationary treatment, except for dialysis and cancer chemotherapy.

Table 6. Data on the adults' health condition by disease groups and districts

Specification	Overall			Cancer			Cerebrovascular diseases		
				C00-D48			I60-I69		
	2009	2010	2011	2009	2010	2011	2009	2010	2011
Wielkopolska	451 694	576 261	703 289	12 211	16 512	24 444	10 901	18 544	26 756
City of Poznan	79 830	118 432	131 884	2 599	3 428	5 788	1 887	4 639	5 764

Table 7. Treated for mental disorders (no drug use) by districts in 2011, according to the basic recognition

Specification	Total	Organic non-psychotic disorders	Organic psychotic disorders
		F00-F09	F03-F06
Wielkopolska	55 039	2 930	5 633
City of Poznan	16 224	891	1 819

Table 8. The causes of hospitalization by age group and gender in the region

Treated by age groups	Tumors					
	C00-D48					
	2009		2010		2011	
	M	F	M	F	M	F
Total (total population)	35 051	43 634	32 471	41 566	32 345	42 047
60-64	6 427	6 144	6 557	6 233	6 344	6 635
65-69	4 490	3 928	4 020	3 443	4 509	3 949
70-74	4 414	3 684	3 886	3 446	3 689	3 292
75-79	2 957	2 420	2 717	2 390	2 974	2 588
80-84	1 350	1 418	1 266	1 405	1 368	1 361
85-	467	641	533	703	635	695

Table 9. Patients treated in mental health outpatient clinics in the region

Specification	Year			Organic non- psychotic disorders	Organic psychotic disorders
		Total	Active care		
Total no of patients	2010	84 974	20 520	4 249	8 786
	2011	54 546	11 591	2 930	5 633
Mental Health Outpatient Clinic for adults	2010	79 071	20 390	4 245	8 786
	2011	49 062	11 468	2 924	5 633
Mental Health Outpatient Clinic for teenagers and children	2010	5 903	130	4	0
	2011	5 484	123	6	0
including:					
patients treated for the first time	2010	18 517	4 289	637	1 502

	2011	14 345	2 612	586	1 143
Mental Health Outpatient Clinic for adults	2010	16 454	4 263	636	1 502
	2011	11 990	2 587	584	1 143
Mental Health Outpatient Clinic for teenagers and children	2010	2 063	26	1	0
	2011	2 355	25	2	0

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- 46.

2.3.Constraints

Several discrepancies in the data on global prevalence of dementia and gaps in our knowledge about epidemiology of exist. Data remain inconsistent for several reasons, which include:

- a) Use of statistical data based on predictions instead of “real” numbers. Misiak et al (2013) has shown that nationwide population – based surveys are not carried out so several countries provide prognostic prevalence estimates, which are based on the percentage of older adults in a given area, diverse screening methods and other diagnostic problems ^{84, 85, 86}

⁸⁴ Lee L. Weston WW, Heckman G, Gagnon M, Lee FJ, Sloka S. Structured approach to patients with memory difficulties in clinical practice. *Can Fam Physician*. 2013; 59: 249 – 254.

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- b) Observed differences in screening methods (e.g. neuropsychological tests) used to diagnose dementia in each epidemiological study^{87, 88}.
- c) Diagnostic problems. Epidemiological studies indicate that dementia (Alzheimer's dementia in particular) is often ignored (e.g. by patient's families) or undetected so approximately 50% of persons meeting diagnostic criteria for AD remain undiagnosed. Similarly, some 30% of all cases of Lewy body dementia, which is the least known form of dementia, are misdiagnosed as Dementia Alzheimer's Type or VaD (accurate diagnosis of the type of dementia can be performed only on autopsy). To add, many patients have concurrent clinical symptoms of two forms of dementia such as AD and VCI or AD and LBD (beta – amyloid plaques, neurofibrillary tangles and white matter lesions or Lewy bodies) so several cases of mixed dementia are reported as included as either VCI or AD^{89, 90, 91, 92}.

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⁹¹ Barreiro – Pareja F, Benito – Leon J, Vega S, Medrano MJ, Roman GC. Incidence and subtypes of dementia in three elderly populations of Central Spain. *J Neurol Sci.* 2008;264:63–72.

⁹² Povova J, Amroz P, Bar M, Pavukova V, Sery O et al. Epidemiological of and risk factors for Alzheimer's disease. A review. *Biomed Pap Med Fac Univ Palacky Olomouc Czech Repub.* 2012;156:108–114.

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Additional data

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3. Clinical aspects of dementia

3.3.Diagnostic criteria

Main clinical criteria for the assessment of all – cause dementia

In a clinical setting various criteria are proposed for diagnosis of dementia. National Institute on Ageing – Alzheimer's Association Recommendations workgroups recommend that the diagnosis of dementia should be given by a skilled clinician based on description of patient's daily affairs taken both from the patient and a knowledgeable informant. Severity of dementia depends on how the symptoms interfere with patient's daily activities both at home and at work ⁹³.

Dementia is diagnosed when the patient manifests cognitive or behavioral symptoms that:

- Interfere with the ability to function at work or at usual activities; and
- Represent a decline from previous levels of functioning and performing; and
- Are not explained by delirium or major psychiatric disorder;
- Cognitive impairment is detected and diagnosed through a combination of (1) history taking from the patient and a knowledgeable informant and (2) an objective cognitive assessment, either a "bedside" mental status examination or neuropsychological testing. Neuropsychological testing should be performed when the routine history and bedside mental status cannot provide a confident diagnosis.

The cognitive or behavioral impairment involves a minimum of two of the following domains:

- a. Impaired ability to acquire and remember new information – symptoms include: repetitive questions or conversations, misplacing personal belongings, forgetting events or appointments, getting lost on a familiar route.
- b. Impaired reasoning and handling of complex tasks, poor judgment – symptoms include: poor understanding of safety risks, inability to manage

⁹³ Povova J, Amroz P, Bar M, Pavukova V, Sery O et al. Epidemiological of and risk factors for Alzheimer's disease. A review. Biomed Pap Med Fac Univ Palacky Olomouc Czech Repub. 2012;156:108–114.

- finances, poor decision – making ability, inability to plan complex or sequential activities.
- c. Impaired visuospatial abilities – symptoms include: inability to recognize faces or objects in direct view despite good acuity, inability to operate simple implements or orient clothing to the body.
 - d. Impaired language functions (speaking, reading, writing) – symptoms include:
difficulty thinking of common words while speaking, hesitations; speech, spelling and writing errors.
 - e. Changes in personality, behavior or comportment – symptoms include uncharacteristic mood fluctuations such as agitation, impaired motivation, initiative, apathy, loss of drive, social withdrawal, decreased interest in previous activities, loss of empathy, compulsive or obsessive behaviors, socially unacceptable behaviors⁹⁴.

3. 2 Diagnostic methods

The diagnosis of dementia and determination of its cause may be difficult and require a lot of research. Dementia can be pre-identify on the basis of Mini Mental State Examination - MMSE, where a score of <24 points can indicate the existence of dementia and the need for further diagnostics. A simple and easy to carry out is the test of drawing a clock. It may be carried out together with the MMSE. Experienced neuropsychologist and cognitive abilities tests are required to confirm the recognition of dementia. The next stage, after the diagnosis of dementia, is to determine its cause. Potentially reversible causes such as metabolic diseases, central nervous system tumors, infections must be excluded and differentiation of dementia with depression, which use a variety laboratory and imaging tests.

⁹⁴ Mckhann GM, Knopman DS, Chertkow H, Hyman BT, Jack JR CR et al. The diagnosis of dementia due to Alzheimer's disease: Recommendations from the National Institute on Ageing – Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimers Dement*. 2011; 7: 263 – 269. doi: 10.1016/j.alz.2011.03.005.

3.3. Risk factors for dementia

Research conducted on the prevalence of dementia syndromes, show its dependence on advanced age. It is the most important risk factor for dementia. Another one is the low level of education. People who are not well educated have low intellectual ability and low intelligence quotient, and therefore are more likely to impair mental functioning in old age. In addition, the low level of education is often accompanied by a neglect of a healthy lifestyle, worse physical conditions and the abuse of drugs. Such persons are infected in particular diseases of the cardiovascular system, causing vascular dementia. In addition to age and level of education, dementia is also associated with the genetic factors. It has been proved that a family history of Alzheimer's disease significantly increases the likelihood of this type of dementia. Hypothyroidism, autoimmune diseases and epilepsy are among somatic and psychiatric diseases that are risk factors for dementia. Atherosclerosis and its complications are factors that especially affect the development of vascular dementia. They lead to both the local cerebral circulation disorders, as well as changes in the systemic circulation. Hyperlipidemia and diabetes favor the development of atherosclerosis, and thus indirectly vascular dementia. Consequently the occurrence of dementia is the result of applying a number of factors responsible for neuronal damage.

Risk factors for Alzheimer's dementia and vascular dementia partially overlap with each other. Therefore, prevention of vascular disease is also a prevention of Alzheimer's disease. Given that the population is ageing and the number of people with dementia is growing, it can be assumed that dementia would not only one of the major public health problem, but also the motivation to research the phenomenon in the near future ⁶⁶.

3.4.Types of dementia

Due to the ambiguous etiology of dementia there is plurality of divisions. The most common distinguishes primary degenerative dementia and secondary dementia. The primary degenerative dementia should include Alzheimer's disease, frontotemporal dementia and Lewy body dementia.

The secondary degenerative dementias may be reversible or irreversible. They include among others, Vascular dementia, dementia in the course of metabolic disorders, dementia

caused by brain injury following trauma, dementia in the course of primary and metastatic brain tumors, dementia caused by the use of drugs or drug poisoning and toxic substances, dementia due to alcohol use or psychoactive substances, dementia in normal pressure hydrocephalus, dementia in the course of CNS infection or systemic diseases.

Table 10. The most common conditions which lead to cognitive impairment in the elderly.

Degenerative brain diseases	Acquired brain diseases	Other potentially reversible diseases
<ul style="list-style-type: none"> • Alzheimer's dementia • Frontotemporal dementia • Parkinson's disease • Huntington's disease • Lewy body dementia 	<ul style="list-style-type: none"> • Vascular dementia <ul style="list-style-type: none"> - Multi-infarct dementia - Binswanger's disease - Generalized atherosclerosis - Myocardial hypothalamus - Vasculitides • Brain damage as a result of the injury, including: <ul style="list-style-type: none"> • Boxer's dementia • Chronic subdural hematoma • Brain tumors <ul style="list-style-type: none"> - Primary and metastatic tumors - Carcinomatosis meningitis - Paraneoplastic encephalitis • Normotensive hydrocephalus 	<ul style="list-style-type: none"> • Metabolic disorders <ul style="list-style-type: none"> - Hypothyroidism - Cushing's syndrome - Hypothyroidism and hyperparathyroidism - Vitamin B12 deficiency - Thiamine deficiency - Nicotinic acid deficiency - Chronic glucose deficiency • Toxic disorders <ul style="list-style-type: none"> - Alcoholic dementia - Organic compounds poisoning - Heavy metals poisoning - Medications and drug poisoning - Dialysis dementia • Dementia in the course of infection (chronic) <ul style="list-style-type: none"> - The HIV - Syphilis - Encephalitis

	<ul style="list-style-type: none"> • Passed transmissible spongiform encephalopathies caused by prions 	<ul style="list-style-type: none"> -Subacute sclerosing panencephalitis • Mental illnesses - Depression - Disorders of consciousness
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Source: L. Bidzan, Choroba Alzheimerowa.(Alzheimer's disease), Poradnik dla lekarzy, Gdańska 2005, s. 26.

3.4.1. Alzheimer's disease. Etiopathogenesis of Alzheimer's disease.

Alzheimer's disease (AD) is considered to be the most common cause of dementia. It is believed that it is responsible for 70-80% of cases the occurrence of dementia. However, in the literature different data can be found. It is due to the advances in methods of diagnosis and differentiation of other diseases, such as dementia caused by Lewy bodies. It is an acquired disease, the cause of which remains unknown, despite intensive research. The risk factors that favor the development of AD are determined. Researchers found out also its genetic predisposition - people with APOE ε4 gene, are more prone to amyloid deposition in the central nervous system, which is found in the form of plaques in the AD patients CNS.

Alzheimer's disease (AD), which is the most common incurable neurodegenerative disease and affects 50% of all individuals with dementia, has been recognized as the most prevalent cause of late – onset dementia^{95, 96}. The characteristic pathological hallmarks of AD include extraneuronal beta – amyloid (senile) plaques (SPs), intraneuronal neurofibrillary tangles (NFTs) and the loss of connections between neurons due to cholinergic neurotransmission abnormalities. Beta – amyloid plaques are aggregates of insoluble deposits of toxic beta-amyloid protein can be observed in the

⁹⁵ Povova J, Amroz P, Bar M, Pavukova V, Sery O et al. Epidemiological of and risk factors for Alzheimer's disease. A review. Biomed Pap Med Fac Univ Palacky Olomouc Czech Repub. 2012;156:108–114.

⁹⁶ Alzheimer's disease. Unraveling the mystery. Washington D.C.: U.S. Department of Health and Human Services Publishing, 2008. NIH Publication Number: 08-3782.

spaces between neurons^{97, 98}. Studies on the role beta-amyloid in the disease process suggest it may disrupt synaptic connections between neurons and communication. Research has also led to the development of the so – called amyloid cascade hypothesis. According to this hypothesis, accumulation of beta – amyloid in the brain causes a cascade of processes such as formation of neurofibrillary tangles, disrupted neuronal activity, loss of neurons and then intellectual deterioration^{99, 100, 101}. Still, several data suggest that neuritic plaques are not the cause but the result of the disease because may be a way to neutralize beta – amyloid's toxic activity or to decrease its amount in the brain^{102, 103}. Neurofibrillary tangles, the other characteristic formation of an AD brain, contain aberrant hyperphosphorylated microtubule – associated Tau – protein. Tau – protein in an AD brain is the main component of pathological protein threads – aggregated paired helical

⁹⁷ Alzheimer's disease. Unraveling the mystery. Washington D.C.: U.S. Department of Health and Human Services Publishing, 2008. NIH Publication Number: 08-3782.

⁹⁸ Reitz Ch. Alzheimer's disease and the Amyloid Cascade Hypothesis: A Critical Review. *Int J Alzheimers Dis.* 2012: 2012 Article ID 369808 doi:10.1155/2012/369808.
Retrieved from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC35313573/pdf/IJAD2012-369808.pdf>
(Access: 2013.02.30)

⁹⁹ Alzheimer's disease. Unraveling the mystery. Washington D.C.: U.S. Department of Health and Human Services Publishing, 2008. NIH Publication Number: 08-3782.

¹⁰⁰ Reitz Ch. Alzheimer's disease and the Amyloid Cascade Hypothesis: A Critical Review. *Int J Alzheimers Dis.* 2012: 2012 Article ID 369808 doi:10.1155/2012/369808.
Retrieved from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC35313573/pdf/IJAD2012-369808.pdf>
(Access: 2013.02.30)

¹⁰¹ 2012 Alzheimer's disease. Facts and Figures. *Alzheimer's & Dement.* 8 (2012) Retrieved from: http://www.alz.org/downloads/facts_figures_2012.pdf (Access: 2013.03.01)

¹⁰² Alzheimer's disease. Unraveling the mystery. Washington D.C.: U.S. Department of Health and Human Services Publishing, 2008. NIH Publication Number: 08-3782.

¹⁰³ Reitz Ch. Alzheimer's disease and the Amyloid Cascade Hypothesis: A Critical Review. *Int J Alzheimers Dis.* 2012: 2012 Article ID 369808 doi:10.1155/2012/369808.
Retrieved from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC35313573/pdf/IJAD2012-369808.pdf>
(Access: 2013.02.30)

filaments (PH, which binds together and form intracellular neurofibrillary tangles. Neurofibrillary tangles, which damage the neuronal internal transport and communication between neurons.

First, amyloid plaques and neurofibrillary tangles can be found in entorhinal lobe and hippocampus but they later spread to temporal, parietal and frontal lobe^{104, 105, 106, 107, 108}. Currently, the exact causes of Alzheimer's disease and the disease mechanism are not yet well recognized. However, genetic, vascular and psychosocial hypotheses on etiopathogenesis of Alzheimer's disease have been described.

DSM – IV – TR Criteria for the Dementia of the Alzheimer's Type (DAT)

- A. The development of multiple cognitive deficits manifested by both
 - (1) Memory impairment (impaired ability to learn new information or to recall previously learned information)
 - (2) One (or more) of the following cognitive disturbances:
 - (a) Aphasia (language disturbance)
 - (b) Apraxia (impaired ability to carry out motor activities despite intact motor function)
 - (c) Agnosia (failure to recognize objects despite intact sensory function)

¹⁰⁴ Alzheimer's disease. Unraveling the mystery. Washington D.C.: U.S. Department of Health and Human Services Publishing, 2008. NIH Publication Number: 08-3782.

¹⁰⁵ Reitz Ch. Alzheimer's disease and the Amyloid Cascade Hypothesis: A Critical Review. Int J Alzheimers Dis. 2012; 2012 Article ID 369808 doi:10.1155/2012/369808.
Retrieved from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC35313573/pdf/IJAD2012-369808.pdf> (Access: 2013.02.30)

¹⁰⁶ 2012 Alzheimer's disease. Facts and Figures. Alzheimer's & Dement. 8 (2012) Retrieved from: http://www.alz.org/downloads/facts_figures_2012.pdf (Access: 2013.03.01)

¹⁰⁷ Sperling RA, Aisen PS, Beckett LA, Bennett DA, Craft S et al. Toward Defining the preclinical stages of Alzheimer's disease: recommendation from the National Institute on Ageing – Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. Alzheimers Dement. 2011;7:280 – 92. Doi: 10.1016/j.alz.2011.03.003.

¹⁰⁸ Maslow K. Alzheimer's disease facts and figures. Alzheimers Dement. 2008;4:110–133.

- (d) Disturbance in executive functioning (i.e. planning, organizing, sequencing, abstracting).
- B. The cognitive deficits in criteria A1 and A2 each cause significant impairment in social or occupational functioning and represent a significant decline from a previous level of functioning.
- C. The course is characterized by gradual onset and continuing cognitive decline.
- D. The cognitive deficits in Criteria A1 and A2 are not due to any of the following:
 - (1) other central nervous system conditions that cause progressive deficits in memory and cognition (e.g. cerebrovascular disease, Parkinson's Disease, Huntington's disease, subdural hematoma, normal pressure hydrocephalus, brain tumor)
 - (2) systemic conditions that are known to cause dementia (e.g. hypothyroidism, vitamin B or folic acid deficiency, niacin deficiency, hypercalcemia, neurosyphilis, HIV infection)
 - (3) substance induced conditions.
- E. The deficits do not occur exclusively during the course of delirium.
- F. The disturbance is not better accounted for by another Axis I disorder (e.g. Major Depressive Episode, Schizophrenia).

Code is based on presence or absence of clinically significant behavioral disturbance:

294.10 Without Behavioral Disturbance: if the cognitive disturbance is not accompanied by any clinically significant behavioral disturbance

294.11 With Behavioral Disturbance: if the cognitive disturbance is accompanied by a clinically significant behavioral disturbance (e.g. wandering, agitation)

DAT with Late Onset can be diagnosed if onset is after age 65¹⁰⁹.

¹⁰⁹ Diagnostic and Statistical Manual of Mental Disorders, fourth Edition, Text Revision, Copyright 2000 American Psychiatric Association
First MB, Frances A, Pincus HA The Essential Companion to The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision DSM – IV – TR Guidebook Washington DC American Psychiatric Association Publishing 2004).

Hypotheses on the etiopathogenesis of Alzheimer's disease and other dementias

Genetic risk factors of late – onset Alzheimer's disease.

So far, Apolipoprotein E (APoE) gene, which is involved in beta – amyloid clearance (metabolism), is the only gene with a confirmed association with late – onset Alzheimer's disease. Several APoE polymorphisms have been described such as APoE2, APoE3 and APoE4. ApoE2 allele may “protect” individuals against AD because it decreases the risk of developing this condition, ApoE3, in turn, is neutral while APoE4 allele, increases individual susceptibility to Alzheimer's disease. Studies have indicated that APoE4 allele plays a role in several metabolic processes i.e. homeostasis of cholesterol and phospholipids, synaptic integrity, amyloid metabolism, tau phosphorylation, accumulation of neurofibrillary tangles and neuronal survival. Findings have also shown that close relatives of apoE4 carriers affected with AD are at a significantly higher risk of developing this form of dementia than non – carriers. Nonetheless, screening tests for APoE4 are not yet performed routinely. But this gene mutation can be found only in approximately 15 – 20% patients so most individuals affected with AD do not carry the APoE4 mutation^{110, 111, 112, 113, 114}.

Recently, with the development of genome – wide association studies (GWAS), researchers were able to implicate other gene candidates for late – onset AD susceptibility genes such as CLU, PICALM, CR1, BIN1, (ABC) A7, MS4A cluster, C2AP, CD33 or

¹¹⁰ Alzheimer's disease. Unraveling the mystery. Washington D.C.: U.S. Department of Health and Human Services Publishing, 2008. NIH Publication Number: 08-3782.

¹¹¹ Maslow K. Alzheimer's disease facts and figures. *Alzheimers Dement*. 2008;4:110–133.

¹¹² Józwiak A. Dementia in the elderly. *Geriatrics* 2008; 2: 237 – 246.

¹¹³ Karantzoulis S, Galvin JE. Distinguishing Alzheimer's disease from other major forms of dementia. *Expert Reve Neurother*. 11, 2011 downloaded from: <http://expert-reviews.com/doi/pdfplus/10.1586/ern.11.155> (access: 2013.03.12)

¹¹⁴ Paulson HL, Igo I. Genetics of Dementia. *Semin Neurol*. 2011;31:449–460. Doi:10.1055/s-0031-1299784.

EPHA1. Some of them i.e. CLU, CR1, (ABC) A7, MS4A and CD33 have been associated with the immune system functioning and neuroinflammation. Also, some reports suggested CLU, PICALM, BIN1, (ABC) A7 may be connected with lipid metabolism and cholesterol dysregulation while PICALM, BIN1, CLU and C2AP may be involved in the mechanism of synaptic dysfunction. To add, BIN1 may play a role in the formation of neurofibrillary tangles¹¹⁵. These studies shed light on the role of genes in the disease process but future studies are necessary to find out metabolic mechanisms involved in the development of AD.

- **Gender as a risk factor for Alzheimer's disease**

Several observations suggested that females, especially menopausal ones, are 1.5 – 3 times as likely to develop Alzheimer's disease as males so a significant decrease in estrogen levels during menopause may be associated with a higher risk of developing Alzheimer's disease. Some evidence also suggest that estrogen may protect against neuroinflammation^{116, 117, 118, 119}.

- **Vascular hypothesis**

¹¹⁵ Paulson HL, Igo I. Genetics of Dementia. *Semin Neurol.* 2011;31:449–460. Doi:10.1055/s-0031-1299784.

¹¹⁶ Maslow K. Alzheimer's disease facts and figures. *Alzheimers Dement.* 2008;4:110–133.

¹¹⁷ Józwiak A. Dementia in the elderly. *Geriatrics* 2008; 2: 237 – 246.

¹¹⁸ Paulson HL, Igo I. Genetics of Dementia. *Semin Neurol.* 2011;31:449–460. Doi:10.1055/s-0031-1299784.

¹¹⁹ Avramopoulos D. Genetics of Alzheimer's disease: recent advances. *Genome Med.* 2009;1:34. Retrieved from: <http://genomemedicine.com/content/1/3/34> (Access: Feb. 28, 2013)

Reports confirm that correlation between factors which play a role in vascular disease i.e. hypertension, elevated cholesterol, obesity or type 2 diabetes at midlife co – occur with Alzheimer’s dementia in later life^{120, 121}.

- **Other factors**

Other known risk factors include: age, illness in the family, obesity, insulin resistance, lipid disorders, vascular disease and hypertension, the presence of inflammation markers, CNS trauma condition and the presence of Down syndrome [2, 3, 4, 5]. More recent studies have found a correlation of two already known risk factors: the mentioned variant of APOE, elevated blood pressure and the incidence of AD^{122, 123}.

- **The role of lifestyle and environmental factors**

Research studies have indicated that certain lifestyle or behavioral factors such as balanced diet, moderate alcohol intake, social interaction, education and physical activity may play a protective role against AD. Clearly, balanced diet and limited alcohol use are associated with better general health status (healthier arteries, less inflammatory processes and oxidative stress) but the role of adequate social life, education and physical activity as “safeguards” against dementia needs explanation. As far as physical activity is concerned, studies have shown that respondents who practiced some kind of fitness exercises twice a week were less likely to develop dementia than their counterparts who

¹²⁰ Karantzoulis S, Galvin JE. Distinguishing Alzheimer’s disease from other major forms of dementia. Expert Rev Neurother. 11, 2011 downloaded from: <http://expert-reviews.com/doi/pdfplus/10.1586/ern.11.155> (access: 2013.03.12).

¹²¹ Bendin BB, Carlsson CM, Gleason CE, Johnson SC, Sodhi et al. Midlife Predictors of Alzheimer’s disease. Maturitas. 2010;65:131–137. Doi:10.1016/j.maturitas.2009.12.014.

¹²² Maslow K. Alzheimer’s disease facts and figures. Alzheimers Dement. 2008;4:110–133.

¹²³ Józwiak A. Dementia in the elderly. Geriatria 2008; 2: 237 – 246.

did not exercise. Most probably, physical exercise mediated better brain oxygen utilization and kept neurons healthier ^{124, 125, 126, 127}.

The other aforementioned factor, education has also been shown to protect against AD i.e. individuals with more years of education or better “cognitive reserve” were found to have a lesser chance of developing dementia. Here, the role of the so – called “cognitive reserve” was indicated. “Cognitive reserve” was associated with and could result from brain stimulation mediated by high intellectual activity (more years of education, intellectual interests). Brain stimulation advantageously affected neurogenesis, synaptic density and improved flexibility of brain networks so it indirectly prevented intellectually active individuals against cognitive decline due to brain pathology. Some authors also suggested that individuals with cognitive reserve were not just “inoculated” against dementia but it slowed down the disease process so that these individuals remained independent longer despite dementia ^{128, 129, 130}.

The course of Alzheimer’s disease

Alzheimer’s disease process starts several years before clinical symptoms emerge. In the presymptomatic or preclinical stage of Alzheimer’s disease changes such as loss of

¹²⁴ Alzheimer’s disease. Unraveling the mystery. Washington D.C.: U.S. Department of Health and Human Services Publishing, 2008. NIH Publication Number: 08-3782.

¹²⁵ 2012 Alzheimer’s disease. Facts and Figures. Alzheimer’s & Dement. 8 (2012) Retrieved from: http://www.alz.org/downloads/facts_figures_2012.pdf (Access: 2013.03.01)

¹²⁶ Jóźwiak A. Dementia in the elderly. Geriatria 2008; 2: 237 – 246.

¹²⁷ Bendin BB, Carlsson CM, Gleason CE, Johnson SC, Sodhi et al. Midlife Predictors of Alzheimer’s disease. Maturitas. 2010;65:131–137. Doi:10.1016/j.maturitas.2009.12.014.

¹²⁸ Alzheimer’s disease. Unraveling the mystery. Washington D.C.: U.S. Department of Health and Human Services Publishing, 2008. NIH Publication Number: 08-3782.

¹²⁹ Maslow K. Alzheimer’s disease facts and figures. Alzheimers Dement. 2008;4:110–133.

¹³⁰ Bendin BB, Carlsson CM, Gleason CE, Johnson SC, Sodhi et al. Midlife Predictors of Alzheimer’s disease. Maturitas. 2010;65:131–137. Doi:10.1016/j.maturitas.2009.12.014.

neurons and impaired connection between cells accompanied by senile plaques and neurofibrillary tangles in the entorhinal cortex and hippocampus can be found. These changes, which are accompanied by poor communication between nerve cells and neuronal metabolism pathology, later spread to other parts of the brain (temporal, parietal and frontal lobe) thus leading to their damage and atrophy. Recent research studies suggest that presymptomatic individuals may manifest benign sensory, motor or cognitive problems such as impaired ability to detect odors and episodic memory or lower body movement difficulties take place as early as in preclinical AD, yet they are rarely recognized by clinicians ^{131, 132, 133, 134, 135}.

The course of Alzheimer's disease is not the same in each individual but symptoms usually develop over the same stages. Early clinical manifestations of Alzheimer's disease, which emerge when the disease has spread to the entire brain, usually include depressive mood, apathy, irritability and anxiety. Individuals in the initial stage of the disease (Mild Cognitive Impairment due to Alzheimer's disease; amnesic Mild Cognitive Impairment; mild dementia) usually develop increasing problems connected with impaired short – term memory and visual – spatial orientation (confusion about time and place). Deteriorated intellectual functioning also includes losing the ability to think

¹³¹ Alzheimer's disease. Unraveling the mystery. Washington D.C.: U.S. Department of Health and Human Services Publishing, 2008. NIH Publication Number: 08-3782.

¹³² 2012 Alzheimer's disease. Facts and Figures. Alzheimer's & Dement. 8 (2012) Retrieved from: http://www.alz.org/downloads/facts_figures_2012.pdf (Access: 2013.03.01)

¹³³ Sperling RA, Aisen PS, Beckett LA, Bennett DA, Craft S et al. Toward Defining the preclinical stages of Alzheimer's disease: recommendation from the National Institute on Ageing – Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimers Dement*. 2011;7:280 – 92. Doi: 10.1016/j.alz.2011.03.003.

¹³⁴ Jóźwiak A. Dementia in the elderly. *Geriatrics* 2008; 2: 237 – 246.

¹³⁵ Mckhann GM, Knopman DS, Chertkow H, Hyman BT, Jack JR CR et al. The diagnosis of dementia due to Alzheimer's disease: Recommendations from the National Institute on Ageing – Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimer's Dement*. 2011;7: 263 – 269. doi: 10.1016/j.alz.2011.03.005.

logically and verbalization problems, which have a debilitating effect on patient's ability to communicate effectively.

In the second stage of AD (moderate dementia) patients usually display the following symptoms:

- complete short term memory loss (the patient loses the ability to form new memories; anterograde amnesia),
- long term memory loss (patients become forgetful about their own personal history and remember only selected episodes from their childhood)
- progressive agnosia (decreasing ability to recognize others),
- Apraxia (greater difficulty performing complex parallel or sequential tasks such as dressing or other self – care skills),
- wandering,
- circadian rhythm disorder (frequent naps during the day or excessive daytime sleepiness accompanied by sleeplessness and night – time wandering),
- dysphasia (difficulties naming, finding words or wrong word order; impaired power of speech production and perception),
- emotional instability (emotional distress accompanied by crying spells, irritability, anger followed by physical or verbal aggression),
- loss of core critical thinking skills and poor judgment

Many AD patients display neuropsychiatric symptoms such as delusions of theft, delusions of spousal infidelity and delusions of abandonment and hallucinations. These manifestations of the disease may cause anxiety, fear reactions, feelings of awe or aggression. The onset of psychotic symptoms causes significant caregiver distress and often precipitates nursing – home placement ^{136, 137}.

The second stage of the disease is accompanied by patient's loss of functional independence. At this stage of AD, individuals are no longer able to look after themselves; they tend to forget about basic self – care skills such as everyday toileting or washing up.

Patients may also require constant surveillance because they may walk away from home and accidents may occur because they may do something potentially hazardous to themselves or others.

¹³⁶ Maslow K. Alzheimer's disease facts and figures. *Alzheimers Dement*. 2008;4:110–133.

¹³⁷ Józwiak A. Dementia in the elderly. *Geriatrics* 2008; 2: 237 – 246.

The next stage of Alzheimer's disease is called severe dementia. At this stage the motor neuron damage causes walking difficulties, frequent falls and other motor skill impairments. Patients develop incontinence and eventually become bed – ridden ^{138, 139}.

In the terminal stage of the disease patients lose contact with others in their environment and are no longer able to recognize people they know, even the closest family members. They need to have a urinary catheter inserted and lose the swallowing reflex. They usually die as a result of complications of long – term bed confinement and immobilization e.g. cardiovascular problems, respiratory difficulties, aspiration pneumonia or sepsis ¹⁴⁰.

The Report stating that the usage of beta-blockers in treatment of patients with AD and hypertension resulted in less degenerative changes has been published¹⁴¹.

The genetic basis of AD in about 5% of cases is associated with a family history of the disease which occurs at an earlier age.

The following mutations associated with this form of the disease were identified: amyloid precursor protein (APP), the presenilin-1 gene (PS1) and presenilin-2 gene (PS2). Mutations lead to excessive formation of the neurotoxic 42 amino acids variant of the protein instead of the one that consists of 40 amino acids ¹⁴².

Alzheimer's disease is a neurodegenerative disease – it is the effect of not completely understood pathophysiologic processes that results in metabolism disorders, miscommunication between adjacent neurons, there is a loss of synapses and death of neurons. Before the clinical symptoms occur, many changes in the nervous system are

¹³⁸ Alzheimer's disease. Unraveling the mystery. Washington D.C.: U.S. Department of Health and Human Services Publishing, 2008. NIH Publication Number: 08-3782.

¹³⁹ Józwiak A. Dementia in the elderly. *Geriatrics* 2008; 2: 237 – 246.

¹⁴⁰ Ibidem.

¹⁴¹ Karantzoulis S, Galvin JE. Distinguishing Alzheimer's disease from other major forms of dementia. *Expert Review Neurother.* 11, 2011 downloaded from: <http://expert-reviews.com/doi/pdfplus/10.1586/ern.11.155> (access: 2013.03.12)

¹⁴² Avramopoulos D. Genetics of Alzheimer's disease: recent advances. *Genome Med.* 2009;1:34. Retrieved from: <http://genomemedicine.com/content/1/3/34> (Access: Feb. 28, 2013)

created. Formation and accumulation of amyloid or senile plaques are the basic one. Later neurofibrillary tangles appear which is followed by a loss of synaptic connections and necrosis. The course of this chronic progressive disease can be divided it into three stages. The characteristics of each one are shown in the Table 11¹⁴³.

Table 11. The course of this chronic progressive disease

Type of disorder	I – mild dementia	II – intermediate dementia	III – very advanced dementia
Memory	Frequent repetition memory, forgetfulness, inability to recall recent events	Inability to recall, lack of recognition	brak przypominania i rozpoznawania
Language	Difficulties in finding the correct words	Frequent difficulty in finding words. Little difficulty in understanding speech	Poor vocabulary and lack of understanding speech
Visual and spatial	Minor visual-spatial problems in moving through space and the difficulty constructional drawing	Inability to walk independently outside the home, significant problems in drawing the design, the beginning of the dressing problems	Inability to get home, draw or copy and to dress
Implementation	Minor difficulties in evaluation of the situation, small errors in counting and mental acuity, difficulties during such actions as shopping	Lack of money management, complex decision making	Apathy, lack of daily activities, taking care of hygiene, sometimes irritability or aggression
Behaviors	No or minor behavior or personality changes, apathy, listlessness, depression, irritability	Apathy, listlessness, restlessness, in some patients, very high	Apathy, listlessness, restlessness, in some patients very high irritability, depression

¹⁴³ Bendin BB, Carlsson CM, Gleason CE, Johnson SC, Sodhi et al. Midlife Predictors of Alzheimer's disease. Maturitas. 2010;65:131–137. Doi:10.1016/j.maturitas.2009.12.014.

		irritability, severe depression	
Movement	Less severe Parkinson's syndromes	Possible Parkinson's disease	Possible Parkinson's disease, possible seizures, myoclonus

Source: Knopman et al, 2002

Alzheimer's disease treatment is only symptomatic. The registered and used drugs are acetylcholinesterase inhibitors and NMDA receptor partial antagonists. Drugs that cause mood changes such as: antidepressants, anxiolytics, beta-blockers, drugs which eliminate the symptoms of Parkinson's, neuroleptics and anti-epileptic drugs are also used^{144, 145}.

In spite of the treatment prognosis is poor. The disease usually lasts between three and ten years. The immediate cause of death may be such as aspiration pneumonia due to dysphagia or infectious pneumonia.

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¹⁴⁴ Mckhann GM, Knopman DS, Chertkow H, Hyman BT, Jack JR CR et al. The diagnosis of dementia due to Alzheimer's disease: Recommendations from the National Institute on Ageing – Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimer's Dement*. 2011;7: 263 – 269. doi: 10.1016/j.alz.2011.03.005.

¹⁴⁵ First MB, Frances A, Pincus HA. The Essential Companion to The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision DSM – IV – TR Guidebook Washington DC American Psychiatric Association Publishing 2004

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3.4.3. Lewy body dementia

Lewy body dementia (LBD) or Dementia with Lewy bodies (DLB) belongs to the Lewy body spectrum disorders ¹⁴⁶, which can be found in 10 – 30% of all demented patients¹⁴⁷. It is neuropathologically characterized by presence of Lewy bodies, Lewy neurites, beta – amyloid plaques, neurofibrillary tangles and diminished cholinergic neurotransmission in the neocortex. These abnormal changes lead to diminished neuronal activity, impaired connection between nerve cells, loss of brain tissue and brain atrophy ^{148, 149, 150}.

The role of cortical Lewy bodies in the development of dementia was first reported by Okazaki in 1961. These aberrant cortical intracytoplasm inclusions of aggregated insoluble alpha – synuclein remain the main pathogenic hallmark of LBD. In 1984 Kosaka's team indicated that clinical syndrome of dementia characterized by presence of cortical Lewy bodies should become a separate disease entity, called “diffuse Lewy Body disease”. The term Lewy body dementia was finally established during the First International Workshop of the Consortium on DLB in 1996. Then, during the Third

¹⁴⁶ The Lewy body spectrum disorders also include Parkinson's disease (PD). LBD shares many similarities with PD and the relationship between these two conditions remains controversial. The differential diagnosis is based on assessment of onset and duration of motor symptoms but only post – mortem findings are the definitive ones.

¹⁴⁷

¹⁴⁸ Huang Y & Halliday G. Can we clinically diagnose Lewy body dementia yet? *Transl Neurodegener.* 2013;2:4. Retrieved from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3575256/pdf/2047-9158-2-4.pdf> (access: 2013.03.19)

¹⁴⁹ Volpicelli-Daley LA, Luk KC, Patel TP, Tanik SA, Riddle DM. Exogenous alpha – synuclein fibrils induce Lewy body pathology leading to synaptic dysfunction and neuron death. *Neuron.* 2011;71:57–71.

¹⁵⁰ Kaufman DM. *Clinical Neurology.* Sixth Edition. Philadelphia, PA: Saunders Elsevier, 2007. pp.113–128.

International Workshop on DLB in 2005, the participants reached consensus on its clinical symptomatology and established clinical guidelines for the diagnosis ^{151, 152, 153, 154}.

- **Etiology of Lewy body dementia (LBD)**

Lewy body dementia is the second, after AD, most common cause of dementia. It is estimated that 10-20% of the dementia is caused by LBD. The final diagnosis of Lewy body dementia are found in approximately 20% of patients with possible diagnosis of Alzheimer's disease.

It is clinically characterized by the coexistence of symptoms of parkinsonism and dementia. The histopathological examination shows Lewy bodies, intracellular α -synuclein deposits. They are located mainly in the limbic system and the neocortex. Acetylcholine deficiency in the CNS is higher than in AD.

LBD is caused by neuropathological changes in the brain which lead to neuronal loss and subsequent brain atrophy. The risk factors or exact determinants of LBD have not been described yet. However, some genetic findings suggest that familial LBD is caused by mutations in at least seven genes and can be transmitted in an autosomal dominant manner. Furthermore, the risk of developing LBD can be affected by synuclein coding gene polymorphisms. Still, epidemiological studies indicate that this condition most often

¹⁵¹ Huang Y & Halliday G. Can we clinically diagnose Lewy body dementia yet? *Transl Neurodegener.* 2013;2:4. Retrieved from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3575256/pdf/2047-9158-2-4.pdf> (access: 2013.03.19)

¹⁵² Volpicelli-Daley LA, Luk KC, Patel TP, Tanik SA, Riddle DM. Exogenous alpha – synuclein fibrils induce Lewy body pathology leading to synaptic dysfunction and neuron death. *Neuron.* 2011;71:57–71.

¹⁵³ Kaufman DM. *Clinical Neurology.* Sixth Edition. Philadelphia, PA: Saunders Elsevier, 2007. pp.113–128.

¹⁵⁴ Sokół – Szawłowska M, Poleszczuk A. Difficult Road to diagnosing Lewy body dementia. Case report. *Psychiatr Pol.* 2013;47:147–158.

occurs sporadically so being a family member of a person affected with LBD does not significantly increase the risk of developing this form of dementia^{155, 156, 157}.

- **Symptomatology of Lewy body dementia**

The main clinical features of LBD include progressive dementia which interferes with patient's daily affairs or activities of daily living (ADLs) accompanied by at least two of the following core symptoms: (1) fluctuating cognition (FC): distinct differences between patient's best and worst performance¹⁵⁸ or marked variations in patient's alertness; (2) recurrent vivid hallucinations, visual and auditory illusions or distinct visuospatial difficulties¹⁵⁹; and (3) spontaneous extrapyramidal (parkinsonian) signs (masked face, loss of spontaneous movement, disturbed gait, rigidity, postural instability). Other clinical symptoms, which support the diagnosis of LBD comprise:

- severe neuroleptic sensitivity¹⁶⁰,
- REM sleep behavior disorder,
- repeated falls and syncope,

¹⁵⁵ Volpicelli-Daley LA, Luk KC, Patel TP, Tanik SA, Riddle DM. Exogenous alpha – synuclein fibrils induce Lewy body pathology leading to synaptic dysfunction and neuron death. *Neuron*. 2011;71:57–71.

¹⁵⁶ Beyer K, Domingo – Sabat M & Ariza A. Molecular Pathology of Lewy Body Diseases. *Int J Mol Sci*. 2009;10:724–745. doi:10.3390/ijms10030724.

¹⁵⁷ Paulson HL, Igo I. Genetics of Dementia. *Semin Neurol*. 2011;31:449–460. Doi:10.1055/s-0031-1299784.

¹⁵⁸ The term refers to variations in patient's functioning. Patients display excessive symptoms such as sleepiness, "staring into space", "lethargy", unresponsiveness during the day or behavioral confusion but at other times they manifest near pre – morbid level functioning. Clinical tests such as Clinician Assessment of Fluctuation Scale or The Mayo Fluctuations Composite Scale can be used to make the diagnosis of FC accurate.

¹⁵⁹ Hallucinations, which remain a very common and distinct feature of LBD, focus on people, children or animals and may cause patient's agitation. They may be related to presence of Lewy bodies in temporal lobe the amygdala and decreased neocortical cholinergic activity. The Neuropsychiatric Inventory (NPI) is commonly utilized to evaluate visual hallucinations in clinical settings.

¹⁶⁰ Severe sensitivity to 1st generation neuroleptics, which occurs in 30 to 50% of DLB patients, is manifested as an abrupt drowsiness, increased confusion or parkinsonian signs such as muscle rigidity. This phenomenon may be related to dopamine receptor (D2) dysfunction and leads to fatality in patients with unrecognized LBD.

- unexplained loss of consciousness,
- severe autonomic dysfunction, e.g., orthostatic hypotension, urinary incontinence,
- hallucinations in other modalities¹⁶¹,
- systematized delusions focused on strangers or visitors at home and
- depression ¹⁶², ¹⁶³, ¹⁶⁴, ¹⁶⁵.

As mentioned before, LBD is identified by presence of (1) aberrant cortical Lewy bodies with deposits of toxic alpha – synuclein, (2) pathological Lewy neurites and (3) impaired neocortical cholinergic activity. Lewy bodies first spread to cortical areas, the brainstem and then to amygdala while Lewy neurites are seen in the limbic cortex, subcortical nuclei and in hippocampal fields CA2 and CA3. These structures eventually affect the entire brain. They are often accompanied by beta – amyloid plaques and neurofibrillary tangles, which may cause overlapping symptoms of AD. Neurodegeneration of brainstem leads to increasing parkinsonian symptoms while cortical changes are associated with dementia ¹⁶⁶, ¹⁶⁷.

¹⁶¹ Auditory hallucinations (banging, knocking a doorbell or footsteps) may be related to presence of Lewy bodies in the temporal lobe, in the amygdala and decreased neocortical cholinergic activity. The Neuropsychiatric Inventory (NPI) is commonly used to screen for visual hallucinations and evaluate their characteristics such as intensity and severity;

¹⁶² Huang Y & Halliday G. Can we clinically diagnose Lewy body dementia yet? *Transl Neurodegener.* 2013;2:4. Retrieved from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3575256/pdf/2047-9158-2-4.pdf> (access: 2013.03.19)

¹⁶³ Volpicelli-Daley LA, Luk KC, Patel TP, Tanik SA, Riddle DM. Exogenous alpha – synuclein fibrils induce Lewy body pathology leading to synaptic dysfunction and neuron death. *Neuron.* 2011;71:57–71.

¹⁶⁴ Kaufman DM. *Clinical Neurology.* Sixth Edition. Philadelphia, PA: Saunders Elsevier, 2007. pp.113–128.

¹⁶⁵ Sokół – Szawłowska M, Poleszczuk A. Difficult Road to diagnosing Lewy body dementia. Case report. *Psychiatr Pol.* 2013;47:147–158.

¹⁶⁶ Sokół – Szawłowska M, Poleszczuk A. Difficult Road to diagnosing Lewy body dementia. Case report. *Psychiatr Pol.* 2013;47:147–158.

¹⁶⁷ Beyer K, Domingo – Sabat M & Ariza A. Molecular Pathology of Lewy Body Diseases. *Int J Mol Sci.* 2009;10:724–745. doi:10.3390/ijms10030724.

The exact temporal course of symptoms of LBD is different in each patient depending on the sequence of brain area affection. Yet, it follows a general pattern as dementia progresses over time ¹⁶⁸, ¹⁶⁹, ¹⁷⁰. Early symptoms of LBD include REM sleep disorder (patients move or speak while asleep), fluctuating attention (sudden changes in alertness), marked problems in visuospatial orientation and visual hallucinations. Patient's cognitive status may initially appear near – normal but symptoms of dementia such as short – term memory decline and impaired verbal fluency soon emerge. Also, individuals with LBD develop “Parkinson – like” loco – motor signs (i.e. dysarthria, akinesia, unstable gait and postural instability which increase their risk for falling) and depression (i.e. irritability, apathy, low mood and affective changes or abnormal appetite). These symptoms, along with manifestations of psychosis and steady intellectual decline, severely compromise their quality of life. In the middle stage of dementia, patients' functional status and cognitive functioning gradually worsen so they need to be assisted in all their daily activities 24 – hours a day. Finally, in the terminal stage of the disease individuals with LBD spend most of their time in bed. They have a urinary catheter and a naso – gastral tube inserted due loss of basic physiological reflexes such as dysphagia. Their death, which occurs approximately within eight years of diagnosis, most often

¹⁶⁸ Kaufman DM. Clinical Neurology. Sixth Edition. Philadelphia, PA: Saunders Elsevier, 2007. pp.113–128.

¹⁶⁹ Sokół – Szawłowska M, Poleszczuk A. Difficult Road to diagnosing Lewy body dementia. Case report. *Psychiatr Pol.* 2013;47:147–158.

¹⁷⁰ Beyer K, Domingo – Sabat M & Ariza A. Molecular Pathology of Lewy Body Diseases. *Int J Mol Sci.* 2009;10:724–745. doi:10.3390/ijms10030724.

results from complications of long – term immobilization such as cardiac events, respiratory difficulties, aspiration pneumonia or sepsis ^{171, 172, 173, 174}.

Clinically, there are typically specific visual hallucinations (even 60% of patients) and rarely hallucinations of other senses and systematized delusions. Parkinsonian syndrome is symmetrical, not very severe, the study does not indicate a tremor. There are frequent falls, syncope occur (as opposed to AD). At the onset of the disease is dominated by disturbance in attention, executive function, characterized by the large changes in the level of attention. In the initial phase of the disease is not aware of short-term memory problems. The diagnosis of LBD is used McKeith criteria, the final diagnosis is not possible after the histopathology ¹⁷⁵. The presence of Lewy bodies does not equal LBD recognition. α - synuclein deposits also occur in Parkinson's disease and in Hallervorden-Spatz disease.

Table 12. McKeith criteria for Lewy body dementia

McKeith criteria for Lewy body dementia:
1. Main symptoms:

¹⁷¹ Huang Y & Halliday G. Can we clinically diagnose Lewy body dementia yet? Transl Neurodegener. 2013;2:4. Retrieved from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3575256/pdf/2047-9158-2-4.pdf> (access: 2013.03.19)

¹⁷² Volpicelli-Daley LA, Luk KC, Patel TP, Tanik SA, Riddle DM. Exogenous alpha – synuclein fibrils induce Lewy body pathology leading to synaptic dysfunction and neuron death. Neuron. 2011;71:57–71.

¹⁷³ Kaufman DM. Clinical Neurology. Sixth Edition. Philadelphia, PA: Saunders Elsevier, 2007. pp.113–128.

¹⁷⁴ Sokół – Szawłowska M, Poleszczuk A. Difficult Road to diagnosing Lewy body dementia. Case report. Psychiatr Pol. 2013;47:147–158.

¹⁷⁵ Kaufman DM. Clinical Neurology. Sixth Edition. Philadelphia, PA: Saunders Elsevier, 2007. pp.113–128.

<ul style="list-style-type: none"> • dementia, progressive cognitive impairment, significantly worsening the patient's functioning in society and at work; • explicit and persistent memory disorders occur with the progression of the disease and are not necessary to identify at an early stage of LBD; • deficits in attention, frontal-subcortical, visuospatial functions are evident
2. Basic symptoms:
<ul style="list-style-type: none"> • fluctuating course of cognitive impairment; • repeated, clear and detailed visual hallucinations; • symptoms of Parkinson's disease;
3. Assisting symptoms:
<ul style="list-style-type: none"> • repeated falls and syncope; • transient disturbance of consciousness of unknown cause; • increased vegetative disorders (e.g., orthostatic hypotension, urinary incontinence); • systematized delusions; • depression; • other hallucinations (not visual); • relative sparing of the medial temporal lobe on CT scan or MRI;
4. Suggestive symptoms:
<ul style="list-style-type: none"> • a complex behavioral disorders during REM sleep; • high sensitivity to antipsychotics; • low uptake of dopamine transporter in the basal ganglia in SPECT or PET.
5. Symptoms that reduce the likelihood of LBD diagnosis:
<ul style="list-style-type: none"> • Confirmation neuroimaging research or examination cerebrovascular disease;
<ul style="list-style-type: none"> • diagnosis of central nervous system or systemic, satisfactorily explaining the clinical (in whole or in part); • disclosure of a parkinsonian syndrome in a patient for the first time ever at an advanced stage of dementia.
The diagnosis is possible when 1 main symptom and 1 basic or 1 main and ≥ 1 symptom appear.
The diagnosis is likely when 1 main symptom and ≥ 2 basic symptoms or 1 main and ≥ 1 suggestive and ≥ 1 basic symptoms appear.

In Lewy body dementia causal treatment is not possible. In the therapy cholinesterase inhibitors (rivastigmine) are used. Levodopa does not give significant improvement. In case of antipsychotics, often there is a strong sensitivity to traditional neuroleptics.

References:

1. Huang Y & Halliday G. Can we clinically diagnose Lewy body dementia yet? *Transl Neurodegener.* 2013;2:4.
Retrieved from:
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3575256/pdf/2047-9158-2-4.pdf>
(access: 2013.03.19)
2. Volpicelli-Daley LA, Luk KC, Patel TP, Tanik SA, Riddle DM. Exogenous alpha – synuclein fibrils induce Lewy body pathology leading to synaptic dysfunction and neuron death. *Neuron.* 2011;71:57–71.
3. Kaufman DM. *Clinical Neurology.* Sixth Edition. Philadelphia, PA: Saunders Elsevier, 2007. pp.113–128.
4. Sokół – Szawłowska M, Poleszczuk A. Difficult Road to diagnosing Lewy body dementia. Case report. *Psychiatr Pol.* 2013;47:147–158.
5. Beyer K, Domingo – Sabat M & Ariza A. Molecular Pathology of Lewy Body Diseases. *Int J Mol Sci.* 2009;10:724–745. doi:10.3390/ijms10030724.
6. Józwiak A. Dementia in the elderly. *Geriatrics* 2008;2:237–246.
7. Paulson HL, Igo I. Genetics of Dementia. *Semin Neurol.* 2011;31:449–460. Doi:10.1055/s-0031-1299784.

3.4.4. Frontotemporal lobe degeneration (FTLD)

Frontotemporal degeneration, as well as Alzheimer's disease or basal cortical atrophy, or progressive supranuclear palsy is one of the tauopathies. A group of diseases in which tau protein, that damages neuron microtubules, is accumulated. It is a heterogeneous disease with various clinical variants.

It is estimated that the cause of FTLD 8-10% of dementia cases. In most cases it is detected after 65 years. In families, however, it can be detected earlier, at the age of 40. In some

cases the family illnesses, mutation of MAPT gene that encodes the tau protein is observed. Sometimes it is GRN gene encoding progranulin synthesis¹⁷⁶. The occurrence of the disease in the family increases the risk of FTLD 3.5 times¹⁷⁷. The clinical picture is diverse, can be extracted from the four variants: frontotemporal dementia (FTD), a frontal variant of FTLD, temporal variant of FTLD and progressive aphasia with loss of fluency in speech.

Frontotemporal dementia (FTD)

Quite often FTD manifest itself at an early age, is characterized by progressive personality disorder of moderate intensity and aphasia¹⁷⁸. Patients are either apathetic or excited and they cause conflicts. Klüver-Bucy syndrome with memory disorders, gluttony and increased libido caused bilateral temporal lobe damage may also occur. The disease lasts from 2 to 17 years.

Frontal variant of FTLD

It is characterized by personality and behavior disorders, and to a lesser extent, memory disorders. There may be a frontal lobe disorder- disinhibition of behavior, deprivation of distance and criticism, inadequate jocular attitude or depressiveness. Mouthing may also appear. Neurological examination may diagnose primitive reflexes, symptoms of Parkinson's disease and cerebellar syndrome. The disease usually lasts for about 10 years.

Temporal variant of FTLD (semantic dementia)

It is the less common variant of FTLD. The study shows atrophy of temporal lobes and the base of frontal lobes. Symptoms depend on location. If atrophy is in the right temporal lobe the clinical picture is dominated by behavioral disorders. Left lobe atrophy is a

¹⁷⁶ Seelaar H, Kamphorst W, Rosso SM, et al. Distinct genetic forms of frontotemporal dementia. *Neurology*. Oct 14 2008;71(16):1220-6.

¹⁷⁷ Rohrer JD, Guerreiro R, Vandrovcova J, Uphill J, Reiman D, Beck J. The heritability and genetics of frontotemporal lobar degeneration. *Neurology*. Nov 3 2009;73(18):1451-6.].

¹⁷⁸ Boxer AL, Miller BL. Clinical features of frontotemporal dementia. *Alzheimer Dis Assoc Disord*. Oct-Dec 2005;19 Suppl 1:S3-6.

symptom of aphasia. Primitive symptoms may occur. No significant memory impairment, there is verbiage and empty speech with grammatical correctness preserved. There may also be symptoms of the frontal variant ¹⁷⁹.

Progressive nonfluent aphasia (PNA)

Variant with asymmetric atrophy of the left frontal lobe and temporal lobe. Patients understand speech but their own statements are not smooth or grammatically correct, writing and reading appears difficult. At a later stage abnormal behavior as in frontal variant may appear. Neurological examination shows deliberative (primitive) symptoms, and sometimes urinary incontinence and then symptoms of parkinsonism¹⁸⁰.

FTLD diagnosis

Imaging methods are useful, including functional such as SPECT and/or PET. There are McKhann's diagnostic criteria from 2001 available (Table 13).

Table 13. McKhann's FTLD diagnostic criteria

¹⁷⁹ ibidem

¹⁸⁰ ibidem

McKhann's FTL D diagnostic criteria

1) behavioral or cognitive deficit in the form of:

- early and progressive changes in personality and behavior manifested by improper actions and reactions
- early and progressive language disorders manifested by impaired expression of speech or difficulty in naming and understanding of words
- deficit is so severe that it interferes with the functioning of social and professional activity compared to the state before illness occurred

2) the slow onset and progressive course

3) observed disorders are not caused by other disease of the nervous system

4) there are no disturbances in the state of delirium

5) mental disorders were excluded

Treatment

No causal treatment. Methylphenidate shows some efficacy. SSRIs can also be used. ChE inhibitors may be harmful ^{181, 182}.

I. d) Dementia in Pick's disease

It is a chronic neurodegenerative disease with the tau protein deposits and progranulin inclusions. It belongs to the group frontotemporal dementia (FTD). In half the cases, the disease affects more than one family member, which is often associated with the occurrence of mutations in chromosome 17, inherited autosomal dominant. The incidence of Pick's disease in the USA is approximately 5% of all frontotemporal dementia. FTD is the fourth leading cause of dementia and the second in the group of

¹⁸¹ Moretti R, Torre P, Antonello RM, et al. Frontotemporal dementia: paroxetine as a possible treatment of behavior symptoms. A randomized, controlled, open 14-month study. Eur Neurol. 2003;49(1):13-9.

¹⁸² Huey ED, Putnam KT, Grafman J. A systematic review of neurotransmitter deficits and treatments in frontotemporal dementia. Neurology. Jan 10 2006;66(1):17-22.

patients under 60 years of age ¹⁸³. It seems that the disease is more common in the countries of Northern Europe: 7-43 cases/100 thousand populations ¹⁸⁴. Detection of the course of disease and the first symptoms may be difficult, even with MMSE. In the diagnosis of this disease attention should be given to the patients behavior and functioning in the community ¹⁸⁵. Speech problems or apathy can also occur. Currently there are no standards for effective treatment of Pick's disease. In practice, the neuroprotective compounds - vitamins, antioxidants, and drugs depending on the observed symptoms, antidepressants or dopaminergic drugs are used ¹⁸⁶.

I. e) Corticobasal degeneration (CBD)

It is a rare neurodegenerative disease, the incidence is estimated to be less than 1:100 thousand / year ¹⁸⁷. The first symptoms usually appear in the fifth - seventh decade of life, and the disease lasts seven years on average. No significant epidemiological differences depending on sex. There is an extrapyramidal symptom: sluggishness, rigidity, abnormal gait and falls, as well as apraxia and dementia. Symptoms are usually asymmetric, with the progress of the disease may appear on the opposite side. Quite characteristic symptom is an "alien hand syndrome". The incidence of individual symptoms are as follows: parkinsonism - 100% , damage to cortical functions - 93%, apraxia - 82%, abnormal gait

¹⁸³ Graff-Radford NR, Woodruff BK. Frontotemporal dementia. *Semin Neurol.* Feb 2007;27(1):48-57.

¹⁸⁴ Graham A, Hodges J. Frontotemporal dementia. *Psych.* 2008;7(1):24-8.]

¹⁸⁵ Banks S, Weintraub S. Self-awareness and self-monitoring of cognitive and behavioral deficits in behavioral variant frontotemporal dementia, primary progressive aphasia and probable Alzheimer's disease. *Brain Cogn.* Jun 2008;67(1):58-68.]

¹⁸⁶ Scott KR and Barrett AM. Dementia Syndromes: Evaluation and Treatment. *Expert Review of Neurotherapeutics.* 2007;7:407-422.].

¹⁸⁷ Winter, Y. et al. Incidence of Parkinson's disease and atypical parkinsonism: Russian population-based study. *Mov. Disord.* 25, 349–356 (2010).]

- 80%, dystonia - 71%, tremor - 55%, myoclonus - 55%, alien hand syndrome - 42 % ¹⁸⁸. The diagnosis can be especially difficult in early disease and requires a particular differentiation of Parkinson's disease. Definitive diagnosis can be made on the basis of histopathological examination which shows tau protein deposits in neurons and astrocytes of the cortex in the frontotemporal region, particularly in the motor cortex and substantia nigra. Described changes are also accompanied by other pathologies. Effective treatment is unknown. Drugs for Parkinson's disease do not reduce severity of symptoms. Clonazepam may have some effect in the case of myoclonus.

I. f) Parkinson's disease

Parkinson's Disease (PD) is a disorder of the extrapyramidal system. Dementia can be one of its symptoms. These diseases are divided into hypo- and hyperkinetic. The first subgroup is the primary forms of parkinsonism (including PD), parkinsonism accompanies other diseases: progressive supranuclear palsy, dementias such as Alzheimer's disease, other described earlier diseases, secondary parkinsonism and others in the course of hereditary diseases. The group of hyperkinetic movement disorders includes, Huntington's disease.

The main PD symptoms are the ones of musculoskeletal system, such as muscle rigidity, bradykinesia, tremor, resulting from the loss of dopaminergic cells in substantia nigra, leading to a deficiency of dopamine in the striatum. Its incidence increases with age in the population is 120/100 thousand. It increases tenfold after 70 years of age ¹⁸⁹. The diagnosis can be difficult, particularly in the early stages and requires the differentiation of other diseases of the extrapyramidal system, including the units causing dementia, depression,

¹⁸⁸ Jankovic J. Atypical parkinsonian syndromes. 11th Annual Course: A Comprehensive review of movement disorders for the clinical practitioner. Aspen, CO 2001 (materiały konferencyjne)

¹⁸⁹ Wirdefeldt K, Adami HO, Cole P, Trichopoulos D, Mandel J. Epidemiology and etiology of Parkinson's disease: a review of the evidence. Eur J Epidemiol. Jun 2011;26 Suppl 1:S1-58.].

diseases of the musculoskeletal system. Psychological test and imaging methods such as MRI and SPECT are useful in the diagnosis ¹⁹⁰.

Treatment is based on the use of preparations that increase the concentration and / or the half-life of levodopa. Attempts are being made with invasive treatment and electric stimulation of the CNS structures. Drugs from other groups are also used according to the reactions ¹⁹¹, ¹⁹². The duration of the disease is usually 15-20 years.

g) Huntington's disease

It is a genetic, progressive disease with autosomal dominant inheritance characterized the choreic movements, personality disorders and dementia.

HD gene mutations are responsible for the synthesis of huntingtin (its function is not completely understood) and therefore for the disease. Disorders in the GABA-energetic system are believed to be responsible for choreic movements ¹⁹³. The disease diagnosis is based on family history, symptoms of chorea, personality disorders and dementia ¹⁹⁴. Imaging methods (in TK and MRI the ventricular enlargement creates the shape of a butterfly), and DNA testing. The course of disease is chronic, the incidence is 4-8/100

¹⁹⁰ Hauser RA, Grosset DG. [(123) I]FP-CIT (DaTscan) SPECT Brain Imaging in Patients with Suspected Parkinsonian Syndromes. J Neuroimaging. Mar 16 2011].

¹⁹¹ Samanta J, Hauser RA. Duodenal levodopa infusion for the treatment of Parkinson's disease. Expert Opin Pharmacother. Apr 2007;8(5):657-64. Grimes DA, Lang AE. Treatment of early Parkinson's disease. Can J Neurol Sci. Aug 1999;26 Suppl 2:S39-44.

¹⁹² Zesiewicz TA, Sullivan KL, Arnulf I, et al. Practice Parameter: treatment of nonmotor symptoms of Parkinson disease: report of the Quality Standards Subcommittee of the American Academy of Neurology. Neurology. Mar 16 2010;74(11):924-31.

¹⁹³ Quintanilla RA, Johnson GV. Role of mitochondrial dysfunction in the pathogenesis of Huntington's disease. Brain Res Bull. Oct 28 2009;80(4-5):242-7.]

¹⁹⁴ Jason GW, Suchowersky O, Pajurkova EM, et al. Cognitive manifestations of Huntington disease in relation to genetic structure and clinical onset. Arch Neurol. Sep 1997;54(9):1081-8.].

thousand. Symptoms appear about the age 35-45 and it lasts 15-20 years from the time of diagnosis. It is estimated that at least half of that time patient needs care. Treatment is only symptomatic with the emphasized role of antidepressants ¹⁹⁵.

3.4.5. Vascular dementia (VaD)

Vascular dementia (VaD) or Vascular Cognitive Impairment (VCI) is the second most prevalent form of dementia, which accounts for 20 – 40% of all dementias VaD, which is defined as dementia in close temporal relation to hemodynamic or thromboembolic events, is a heterogeneous syndrome including the following subtypes of cerebrovascular disorders:

- Multi – infarct dementia (MID) with symptoms of dementia developing after a series of cortico – subcortical mini – strokes or transient ischemic attack (TIA). MID may be caused by atherothrombotic or cardiac embolic strokes as well as other hemodynamic events. On neurological exam patients present focal neurological symptoms (positive Babinski's reflex, loss of sensation in a limb, dysarthria or hemiparesis). Also, individuals with MID who experienced only few cortical infarcts often manifest deficits in only one distinct domain of intellectual functioning such as impaired memory or disturbed verbalization (the so – called “patchy” cognitive deficits). In MID, cognitive deterioration progresses in a step – wise manner and becomes intermingled with periods of stability.
- Strategic infarct dementia (SID) which follows isolated infarcts in parts of brain that are vital for intellectual functioning such as thalamus, hippocampus, caudate or genu of the internal capsule. In this subtype of VaD, cognitive or behavioral symptoms are related to the affected brain region and develop abruptly (in days to weeks).
- Subcortical Vascular dementia (SVD; Binswanger's disease), a common form of VaD characterized by multiple lacunar infarcts and ischemic white matter lesions. The latter, which remain the main pathological hallmarks of SVD, can be found on magnetic resonance. SVD, which often progresses slowly, is manifested by not only neurological signs (such as imbalanced gait with characteristic falls; impaired loco – motor functioning; urinary incontinence and dysarthria) but also cognitive –

¹⁹⁵ Adam OR, Jankovic J. Symptomatic treatment of Huntington disease. *Neurotherapeutics*. Apr 2008;5(2):181-97.

behavioral symptoms (mental slowness with attention deficit; personality changes; mood fluctuations and frequent depression). Both cognitive disturbances and depression in the course of SVD have been linked to characteristic brain lesions in cortico – subcortical circuit and deep white matter.

- Hypoperfusion dementia, which may be associated with history of unstable blood pressure or orthostatic hypotension leading to partial ischemia and then to incomplete infarct. Symptoms of hypoperfusion dementia usually include intellectual decline (mental slowness, impaired memory and attention, verbalization problems), compromised functional status (impaired visuospatial orientation and activities of daily living) and depressiveness (lack of motivation and apathy) ^{196, 197, 198}.

As mentioned before, Vascular Cognitive Impairment is characterized by brain infarcts and ischemic white matter lesions. The exact timeline of VCI varies in each affected individual depending on several factors such as type of lesions and brain area affectation. Yet, it follows a general pattern as dementia progresses over time. Early symptoms of Vascular dementia include neurological signs, mental slowness and non – cognitive features such as apathy, depressiveness or emotional disability. As dementia progresses, patients develop more and more problems with their activities of daily living (ADLs) due to apraxia and their cognitive difficulties such as short – term memory impairment or dysphasia intensify. Consequently, patients' functional status is severely compromised so they need assistance in all their everyday asks. Furthermore, they may demonstrate psychiatric symptoms, which are often accompanied by challenging behavior (agitation, aggressiveness, resistance or wandering) ¹⁹⁹.

- **The course of Vascular dementia**

¹⁹⁶ Lee AY. Vascular dementia. Chonnam Med J. 2011;47:66-71.

¹⁹⁷ Levine DA & Langa KM. Vascular Cognitive Impairment: Disease Mechanisms and Therapeutic Implications. Neurotherapeutics. 2011;8:361–373.
doi: 10.1007/s13311-011-0047-z

¹⁹⁸ Józwiak A. Dementia in the elderly. Geriatria 2008;2:237–246.

¹⁹⁹ Ibidem.

The course of Vascular dementia is usually more dramatic than in other dementias. Life expectancy is also shorter because death occurs within approximately four to five years of diagnosis. Individuals in the terminal stage of the disease become frail so they spend most of their time in bed. They frequently display symptoms of agnosia (inability to recognize even the closest relatives) and cannot communicate with others. A urinary catheter and a naso – gastral tube are inserted due to loss of basic physiological reflexes such as dysphagia. The death, which occurs, most often results from typical complications of long – term immobilization such as cardiac events, respiratory difficulties, aspiration pneumonia or sepsis^{200, 201}.

- **Etiopathogenesis of Vascular Cognitive Impairment**

Vascular dementia (VaD) or Vascular Cognitive Impairment (VCI) is an umbrella term implemented to identify a spectrum of cognitive problems related to cardiovascular disease (CVD). In VaD, insufficient blood supply to the brain is related to anoxic brain damage, which in turn causes symptoms of dementia²⁰².

Several risk factors for Vascular dementia also predict vessel disease e.g. white matter lesions (WMLs) have been linked to increasing age, hypertension, diabetes, metabolic syndrome or ischemic disease. These determinants, which can be divided into lifestyle or behavioral factors (lack of physical exercise; smoking; obesity; diabetes) and cardiovascular factors (hypertension; raised LDL cholesterol levels leading to atherosclerosis of blood vessels in the neck; cardiovascular disease) have also been associated with vessel disease. As some authors hypothesized, these factors, along with beta amyloid and nicotinamide adenine dinucleotide phosphate (NADPH) enzyme as mediating agents, may induce vessel disease through pathways of inflammation or oxidative stress. Pathological changes in brain vessels, in turn, may contribute to impaired blood – brain barrier functioning, ischemia, then to ischemia – related brain damage and

²⁰⁰ Lee AY. Vascular dementia. *Chonnam Med J.* 2011;47:66-71.

²⁰¹ Levine DA & Langa KM. Vascular Cognitive Impairment: Disease Mechanisms and Therapeutic Implications. *Neurotherapeutics.* 2011;8:361–373.

doi: 10.1007/s13311-011-0047-z

²⁰² *ibidem.*

intellectual decline. The role of genetic factors has also been analyzed. Here, some research studies suggested that genes associated with the risk of AD such as APoE3 APoE4 may play a role in the etiopathogenesis of VaD, particularly when other behavioral or cardiovascular risk factors i.e. hypertension or diabetes are present. Moreover, several genes were implicated as candidate genes increasing susceptibility for subcortical Vascular dementia. For example, findings have shown that Notch3, which is an autosomal dominant gene associated with cerebral arteriopathy with subcortical infarcts and leukoencephalopathy, also correlated with subcortical VaD. Furthermore TRIM65, TRIM47 and renin – angiotensin system (RAS) genes were frequent predictors of white matter lesions, which remain one of the main pathological hallmarks of VaD. These observations provide strong evidence on etiology of Vascular dementia but more studies are necessary to learn more about the etiology of VaD ^{203, 204, 205, 206}.

Vascular dementia is caused by a brain injury due to secondary circulatory pathologies in the central nervous system. This is the cause of approximately 10-20% of all cases of dementia, but you have to remember that this particular form of dementia can often occur with other diseases that lead to dementia ²⁰⁷. It is estimated that among the elderly up to 40% of dementia cases are mixed dementias resulting from the co-existence of Alzheimer's dementia and Vascular dementia. This can be due to the fact that ischemia

²⁰³ Ibidem.

²⁰⁴ Benisty S, Hernandez K, Viswanathan A, Reyes S, Kurtz A. Diagnostic Criteria of Vascular dementia in CADASIL. *Stroke*. 2008;39:838–844.

²⁰⁵ Schmidt, Freudenberger P, Seiler S, Schmidt R. Genetics of subcortical Vascular dementia. *Exp Gerontol*. 2012;47:873–877. doi: 10.1016/j.exger.2012.06.003

²⁰⁶ Paulson HL, Igo I. Genetics of Dementia. *Semin Neurol*. 2011;31:449–460. doi:10.1055/s-0031-1299784.

²⁰⁷ Schmidtke K, Hull M. Cerebral small vessel disease: how does it progress?. *J Neurol Sci*. Mar 15 2005;229-230:13-20. Jellinger KA. The enigma of vascular cognitive disorder and vascular dementia. *Acta Neuropathol (Berl)*. Apr 2007;113(4):349-88.

can also promote the formation of β -amyloid peptide ²⁰⁸. Atherosclerosis is the most common pathology detected in this type of dementia.

We can distinguish several subtypes of Vascular dementia:

- numerous necrosis outbreaks caused by large vessel occlusion
- single outbreak in the area of vascular necrosis of large vessels
- small vessel cerebrovascular disease, in the course of diabetes, hypertension, vasculitis
- changes of different origin resulting in insufficient blood supply
- numerous small hemorrhagic focus

In the course of Vascular dementia subcortical white matter or basal ganglia are often damaged. The white matter damage results in incontinence, movement disorders and gripping reflexes. The damage to the basal ganglia is the parkinsonism and frontal lobe syndrome, described earlier. There is also a subcortical syndrome, which results in release of information processing, planning and complex tasks execution (e.g. preparing a meal) ^{209, 210}. Another symptom includes aggression and/or irritability, apathy, withdrawal. The dynamics of the disease is variable. There may be sudden, abrupt deterioration arising because of the new area of necrosis. MRI, TK imaging plays an important role in diagnostic. In some cases, it is difficult to differentiate it from the Alzheimer's disease. Diagnostic criteria compiled in the Hachinski scale facilitate the disease differentiation ²¹¹[37].

²⁰⁸ Roman GC. The epidemiology of vascular dementia. Handbook of Clinical Neurology. 2008;vol. 89(3rd series):639-658.

²⁰⁹ Delano-Wood L, Abeles N, Sacco JM, Wierenga CE, Horne NR, Bozoki A. Regional white matter pathology in mild cognitive impairment: differential influence of lesion type on neuropsychological functioning. Stroke. Mar 2008;39(3):794-9.

²¹⁰ Price CC, Jefferson AL, Merino JG, Heilman KM, Libon DJ. Subcortical vascular dementia: integrating neuropsychological and neuroradiologic data. Neurology. Aug 9 2005;65(3):376-82.

²¹¹ Arch Neurol. 2012 Feb;69(2):169-75. doi: 10.1001/archneurol.2011.1698. Epub 2011 Oct 10. Optimizing the Hachinski Ischemic Scale. Hachinski V, Oveisgharan S, Romney AK, Shankle WR.]

Table 14. Hachinski scale

Symptom	Points
sudden onset	2
abrupt worsening	1
disorders fluctuations	2
confusion at night	1
fairly good maintaining of personality	1
depression	1
somatic symptoms	1
pathological laughing or crying	1
hypertension in medical history	1
stroke in medical history	2
symptoms of atherosclerosis	1
focal symptoms	2
focal signs	2
Alzheimer's disease ≤ 4 points	up to 18
Vascular dementia ≥ 7 points	

Source: Arch Neurol. 2012 Feb;69(2):169-75. doi: 10.1001/archneurol.2011.1698. Epub 2011 Oct 10.
Optimizing the Hachinski Ischemic Scale. Hachinski V, Oveisgharan S, Romney AK, Shinkle WR.]

The incidence of post-stroke dementia is about 20% within 3 months after stroke and grows over time.

The symptoms observed in a patient - depend on the location of ischemia²¹².

3.4.5. Infections of the central nervous system

3.4.5.1. Creutzfeldt-Jakob disease (CJD)

The disease is transmissible spongiform encephalopathies (TSEs). This is due to the presence of the prion - infectious protein particles, which accumulates in the central

²¹² Ibidem.

nervous system in the improper conformation. In CJD PrP^{Sc} occurs ²¹³. There are four forms of the disease: sporadic (sCJD), familial (fCJD), iatrogenic (iCJD) and variant (vCJD). The familial form of the disease is likely to cause mutation of PRNP gene encoding the prion protein PrP. The iatrogenic forms occurred in patients treated with preparations containing human growth hormone, or more rarely as a complication after CNS surgery in the form of progressive cerebellar syndrome. The cause of vCJD was passing of prions in the meat of cows suffering from bovine spongiform encephalopathy (BSE, also known as "mad cow disease"). It is believed that the sensitivity of the zoonotic infection is also associated with a mutation in the PRNP gene. The most common form is sporadic (spontaneous), which is found in over 90% of cases of CJD. The sCJD incidences are estimated 0.5-1:1 million populations ²¹⁴. The diagnosis can be based on the most common (70%) occurring triad of symptoms: the occurrence of dementia with myoclonus and characteristic EEG recording ²¹⁵. In the initial period non-specific symptoms like sleepiness, tiredness, and weakness may be observed. There are also cases of severe skin itching. The course of the disease is short and lasts about 11 years ²¹⁶. The vCJD is different so different diagnostic criteria are used to identify this form (Table 15).

Table 15. The vCJD is different so different diagnostic criteria

I.	A. Progressive neuropsychiatric disease
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²¹³ Sikorska B, Knight R, Ironside JW, Liberski PP. Creutzfeldt-Jakob disease. Adv Exp Med Biol. 2012;724:76-90.]

²¹⁴ Centers for Disease Control and Prevention. Fact Sheet: New Variant Creutzfeldt-Jakob Disease. Centers for Disease Control and Prevention. Available at <http://www.cdc.gov/>.]

²¹⁵ Will RG, Ironside JW, Zeidler M, Cousens SN, Estibeiro K, Alperovitch A, Paser S, Pochiari M, Hofman A, Smith PG. A new variant of Creutzfeldt-Jakob disease in the UK. „Lancet”. 347, s. 921-925, 1996.]

²¹⁶ Liberski P. Choroba Creutzfeldta-Jakoba i inne choroby wywołane przez priony – pasażowalne encefalopatie gąbczaste (Creutzfeldt-Jakob disease and other diseases caused by prions - transmissible spongiform encephalopathies). Lublin: Czelej, 2003.

	B. Course of the disease > 6 months C. Routine tests do not suggest an alternative diagnosis D. Lack of anamnesis suggesting a potential source of iatrogenic infection
II.	A. Early psychiatric symptoms (depression, anxiety, apathy, withdrawal, hallucinations) B. Endured pain symptoms (pain, unpleasant dysesthesias) C. Ataxia D. Myoclonus, chorea or dystonia E. Dementia
III.	A. EEG does not show the typical sCJD pattern B. MRI increased signal on both sides in the pulvinar nuclei
Recognition sure when: IA (progressive neuropsychiatric disease + neuropathological confirmation of vCJD (spongiform change and intense accumulation of PrP in the presence of florid plaques in the brain and cerebellum); Recognition probable when: I + 4/5 z II + IIIA + IIIB; Recognition possible when: I + 4/5 of II + IIIA. Reference: Paweł P. Liberski: Choroba Creutzfeldta-Jakoba i inne choroby wywołane przez priony – pasażowalne encefalopatie gąbczaste (Creutzfeldt-Jakob disease and other prion diseases - transmissible spongiform encephalopathies).	

Source: Liberski P. Choroba Creutzfeldta-Jakoba i inne choroby wywołane przez priony – pasażowalne encefalopatie gąbczaste (Creutzfeldt-Jakob disease and other diseases caused by prions - transmissible spongiform encephalopathies). Lublin: Czelej, 2003.

The valuable examination for the diagnosis can be a MRI of CNS. It shows pathognomonic sign for CJD symptom - a pulvinar sign, or the presence of a hyperintense signal from the pulvinar nuclei ²¹⁷.

3.3.5.2. Encephalopathy associated with HIV disease and AIDS dementia complex (ADC)

²¹⁷ Tschampa HJ, Zerr I, Urbach H. Radiological assessment of Creutzfeldt-Jakob disease.. „Eur Radiol”. 17. 5, s. 1200-11, 2007. doi:10.1007/s00330-006-0456-2. PMID 17093966.]

The symptoms are due to the intrusion of HIV into the CNS. It is suggested that the virus is transported within macrophages and/or leukocytes. After release and amplification HIV infects CNS cell: oligodendrocytes, microglia, astrocytes and neurons. It has been shown that the HIV virus most often occurs within the frontal cortex, basal ganglia and the thalamus where localizes itself in the gray and white matter. The mechanism in which the virus affects the CNS cells remains unclear. The protein molecules produced by the virus are being tested as a possible neurotoxin ²¹⁸. The second hypothesis is an autoimmune reaction that causes the disorder. The latter one is confirmed by the presence of antibodies that act against components of the nervous system in AIDS patients with dementia, and which were not detected in the patients without dementia ²¹⁹. Detection of infection is possible by examining the cerebrospinal fluid. Dementia usually appears at the end of the disease. It was a common cause of death before the modern anti-viral drugs were introduced. The occurrence of dementia is associated with the presence of other symptoms and variations in the underlying disease - such as anemia. At this time the uncertain risk factor for accelerated progression of dementia is the female gender ²²⁰. The spectrum of this disorders is wide, the form of asymptomatic, mild cognitive impairment by, to severe dementia. The clinical symptoms of dementia often appear as impaired memory and abstract thinking, speech fluency disorders and/or decision making disorders. Mood and sleep disorders may also appear. These symptoms may be accompanied by movement disorders such as weakness or imbalance. Treatment includes mainly treating the main disease. Antidepressant drugs, anxiolytics or neuroleptics are rarely used. Currently, dementia occurs more frequently in patients from countries with a poor standard of HIV treatment²²¹.

²¹⁸ Di Rocco A, Werner P. Hypothesis on the pathogenesis of vacuolar myelopathy, dementia, and peripheral neuropathy in AIDS. *J Neurol Neurosurg Psychiatry*. Apr 1999;66(4):554.

²¹⁹ Schutzer SE, Brunner M, Fillit HM, Berger JR. Autoimmune markers in HIV-associated dementia. *J Neuroimmunol*. May 2003;138(1-2):156-61.

²²⁰ Stern Y, McDermott MP, Albert S, Palumbo D, Selnes OA, McArthur J, et al. Factors associated with incident human immunodeficiency virus-dementia. *Arch Neurol*. Mar 2001;58(3):473-9.

²²¹ Ibidem.

3.3.5.3. Progressive paralysis in the course of secondary or tertiary syphilis

Nowadays in developed countries neurosyphilis is extremely rare cause of dementia. It can take four forms: meninges inflammation, meningo-vascular inflammation, spinal atrophy, and gumma. In some cases it may be asymptomatic. In the course of the disease movement disorders, urinary incontinence, ataxia and symptoms of dementia such as mood and judgment disorders or personality changes may appear. Serological tests are useful in diagnosis. Well-run treatment leads to stabilization of the clinical picture.

3.3.5.4. Other infections that can cause dementia symptoms:

Numerous infections, including opportunistic viral and fungal infections can be the cause of dementia ²²². The literature enumerates also tuberculosis, fungi *Cryptococcus*, *Toxoplasma Gondii* infection ^{223, 224, 225}.

3.3.6. Injuries

The cause of dementia may be single severe injuries, but also repeated with a lower intensity. An example would be *dementia pugilistica* or boxer's dementia. The mechanism is probably complex and includes injuries, hematomas, formation of senile plaques and

²²² HIV-associated central nervous system diseases in the era of combination antiretroviral therapy. Tan IL, McArthur JC. Eur J Neurol. 2011 Mar;18(3):371-2.

²²³ Cryptococcal meningitis misdiagnosed as Alzheimer's disease: complete neurological and cognitive recovery with treatment. Hoffmann M, Muniz J, Carroll E, De Villasante J. J Alzheimers Dis. 2009;16(3):517-20.

²²⁴ Central nervous system tuberculosis masquerading as primary dementia: a case report. Sethi NK, Sethi PK, Torgovnick J, Arsura E. Neurol Neurochir Pol. 2011 Sep-Oct;45(5):510-3.

²²⁵ Unusual cause of dementia in an immunocompetent host: toxoplasmic encephalitis. Habek M, Ozretić D, Zarković K, Djaković V, Mubrin Z. Neurol Sci. 2009 Feb;30(1):45-9.

other pathologies. In addition to cognitive impairment, parkinsonian symptoms, abnormal gait and slurred speech may occur ²²⁶.

3.3.7. Normal pressure hydrocephalus (NPH)

Normal pressure hydrocephalus is manifested by the characteristic triad of symptoms (Hakim's triad). They include dementia, impaired gait and urinary incontinence. Hakim's triad may be accompanied by a variety of focal symptoms. Symptoms may grow slowly, depending on the initial cause, which makes their differentiation from Alzheimer's disease and other neurodegenerative diseases difficult. The cause of NPH may remain unknown (idiopathic hydrocephalus), or may be due to subarachnoid hemorrhage, head trauma, skull tumors or neuroinfections ²²⁷.

3.3.8. Nutritional deficiencies and metabolic disorders that cause dementia.

One of the most common reversible dementia is caused by the vitamin B12 deficiency ²²⁸. It can be caused by improper diet, malabsorption or renal failure ²²⁹. Wernicke-Korsakoff syndrome caused by prolonged abuse of alcohol is a condition in which the symptoms of dementia occur. Pathomechanism of this syndrome continues to be investigated. The probable causes of the CNS damage are both neurotoxic effects of alcohol and vitamin B1 deficiency ²³⁰.

In case of dementia, the role of the diagnosis of thyroid diseases, renal and hepatic dysfunction is emphasized due to the fact that these dysfunctions are also the cause of

²²⁶ Corsellis JA, Bruton CJ, Freeman-Browne D (August 1973). "The aftermath of boxing". *Psychological Medicine* 3 (3): 270–303. doi:10.1017/S0033291700049588. PMID 4729191

²²⁷ Marmarou A, Young HF, Aygok GA. Estimated incidence of normal-pressure hydrocephalus and shunt outcome in patients residing in assisted-living and extended-care facilities. And which demographic gets this most? *Neurosurgical Focus* 2007; 22: 1-8.

²²⁸ Srikanth S, Nagaraja AV. A prospective study of reversible dementias: frequency, causes, clinical profile and results of treatment. *CMAJ*. 1998 Sep 22;159(6):657-62.

²²⁹ Killen JP, Brenninger VL. Vitamin B12 deficiency.. *N Engl J Med*. 2013 May 23;368(21):2040-1. doi: 10.1056/NEJMc1304350#SA1.

²³⁰ Ridley NJ, Draper B, Withall A. Alcohol-related dementia: an update of the evidence. *Alzheimers Res Ther*. 2013 Jan 25;5(1):3. [Epub ahead of print].

CNS dysfunctions. Especially hypothyroidism in elderly people can remain undiagnosed, and the symptoms are translated into changes resulting from age or wrongly diagnosed as a result of a neurodegenerative disease. There is research conducted on how the concentration of thyroid hormones may affect the clinical picture of Alzheimer's disease

²³¹.

Summary

As the available research show, the incidence of dementia increases with age so the diagnosis and treatment of diseases that cause these symptoms becomes a problem of societies where life expectancy is increasing. This is a serious issue because there are numerous factors that cause dementia. Diagnostics that may be complicated and expensive is necessary in each case to determine whether effective pharmacological and non-pharmacological treatment is possible.

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 - a. doi: 10.1007/s13311-011-0047-z.
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²³¹ Zhang N, Du HJ, Wang JH, Cheng Y A pilot study on the relationship between thyroid status and neuropsychiatric symptoms in patients with Alzheimer disease. *Chin Med J (Engl)*. 2012 Sep;125(18):3211-6.

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3.5.Treatment of Dementia

3.5.1. Pharmacological Treatment

Currently, there are no pharmaceuticals which can cure dementia (affect the cause of the disease, reverse its effects i.e. restore patient's lost intellectual functions or stop the neurodegenerative process)^{232, 233}. However, medications such as Donepezil, Galantamine, Rivastigmine and Memantine are used for symptomatic relief. Donepezil, Galantamine and Rivastigmine remain acetyl cholinesterase inhibitors (ChEIs) and affect cholinergic neurotransmission. ChEIs have been initially developed to treat Alzheimer's as a result of studies on the so – called cholinergic hypothesis of AD (cholinergic neurotransmission dysfunction being a key factor in Alzheimer's etiology). Studies demonstrated they can be beneficial for cognitive symptoms of mild to moderate (Donepezil, Galantamine, Rivastigmine), severe Alzheimer's disease (Donepezil) or cognitive and neuropsychiatric manifestations of Lewy Body Dementia. The last pharmaceutical: memantine is glutamate antagonist affecting glutamatergic neurotransmission. It was developed as a result of observations on the role of glutamatergic synapses in AD and has been recommended for patients with moderate to severe AD or LBD. It is most effective, however, when used in combination with donepezil. Both medications are administered orally but some of them are also available in extended – release formulations (galantamine), transdermal patches (rivastigmine) or once-daily dosing formulation (donepezil). The most common side-effects include gastrointestinal problems or anorexia (ChEIs) or hypertension, headache, sleepiness,

²³² Sadowsky CH, Galvin JE. Guidelines for the management of cognitive and behavioral problems in dementia. JABFM 2012;3:350–366.

²³³ Brady R, Weinman J. Adherence to Cholinesterase Inhibitors in Alzheimer's Disease: A Review. Dement Geriatr Cogn Disord 2013;35:351–363 DOI: 10.1159/000347140

dizziness (memantine). The mode of dispensation or severity of side effects the patient experiences influence adherence to treatment^{234, 235, 236}.

Vaccination therapy against beta – amyloid deposition

At present, clinical trials are underway which look for vaccination against beta – amyloid deposition, which is often viewed as a causative agent of Alzheimer’s Disease. The goal of immunization therapy is to remove beta – amyloid deposits from brain. It is suggested to boost their effectiveness, these vaccination should be administered to patients in the preclinical phase of dementia before the disease takes hold ²³⁷.

Treatment with acetylcholinesterase inhibitors is for people with MMSE scores between 26 and 10 memantine for MMSE scores below 14. There are no restrictions in Poland for the reimbursement of these treatments for people living alone or in nursing homes. Also, prescriptions can be made by any doctor whether for treatment initiation or treatment continuation.

Table 16. Treatment of dementia²³⁸

Prescription and reimbursement	Donepezil	Rivastigmine	Galantamine	Memantine
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²³⁴ Sadowsky CH, Galvin JE. Guidelines for the management of cognitive and behavioral problems in dementia. JABFM 2012;3:350–366.

²³⁵ Brady R, Weinman J. Adherence to Cholinesterase Inhibitors in Alzheimer’s Disease: A Review. Dement Geriatr Cogn Disord 2013;35:351–363 DOI: 10.1159/000347140.

²³⁶ Zupancic M, Mahajan A, Handa K. Dementia with Lewy Bodies: Diagnosis and Management for Primary Care Providers. Prim Care Companion CNS Disord. 2011; 13(5). Doi: 10.4088/PCC.11r01190 downloaded from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3267516/?report=printable> (access: 2013.06.20)

²³⁷ Lambracht – Washington D, Rosenberg RN, Advances in the development of vaccines for Alzheimer’s Disease. Discov Med 2013; 15:319-26

²³⁸ European Commission (2011): MMSOC – Mutual information system on social protection: Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland: Comparative tables

Available	Yes	Yes	Yes	yes
Reimbursed	Only generic	Yes	No	no
Initial reimbursed if prescribed by	No restrictions	No restrictions	No restrictions	No restrictions
Continuing treatment reimbursed if prescribed by	No restrictions	No restrictions	No restrictions	No restrictions
Required examinations	No restrictions	No restrictions	No restrictions	No restrictions
MMSE limits	26-10	26-10	N/A	<10

Source: European Commission (2011): MMSSOC – Mutual information system on social protection: Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland: Comparative tables.

It is stated in the planned Polish National Dementia Strategy that research studies in medicine and social consequences of AD should be developed as well as promoted and financed by the state. Poland is involved in the EU Joint Programme – Neurodegenerative Disease Research (JPND) but not in the Joint Action “Alzheimer Cooperative Valuation in Europe (ALCOVE)”.²³⁹

3.5.2. Non – pharmacological therapy

The non – pharmacological interventions for dementia include psychological methods (behavioral therapy to improve communication and to reduce destructive behavior; reminiscence techniques and reality orientation to improve intellectual functioning or validation therapy) or eclectic methods such as art therapy (e.g. music therapy) and multisensory therapy (snoezelen). These methods are applied not only in mild to moderate stages of dementia but also in the severe stage of the disease (especially snoezelen). Also, non – direct methods such as caregiver psycho – education or support have reported benefits in the problems such as “understanding” the disease, reducing caregiver’s physical and psychological burden or prevention of “catastrophic” behavior which often results from patient’s neuropsychiatric symptoms, tension or

²³⁹ ibidem

communication problems between caregiver and care recipient. Studies suggest non – pharmacological methods can improve patients cognitive functioning but they can be particularly effective in the therapy of behavioral manifestations. These methods are applied alone or in combination with pharmacological therapy. Still, systematic empirical studies in clinical settings (randomized trials on large groups of patients) have yet to confirm their effectiveness^{240, 241, 242}.

²⁴⁰ Sadowsky CH, Galvin JE. Guidelines for the management of cognitive and behavioral problems in dementia. JABFM 2012;3:350–366.

²⁴¹ Clarke L, Bayer A, Burns A, Corbett A, Jones R et al. Goal – oriented cognitive rehabilitation in early – stage dementia: study protocol for a multi – centre single – blind randomized controlled trial (GREAT). Trials.2013; 14:152. Doi: 10.1186/1745-6215-14-152. Retrieved from: www.ncbi.nlm.nih.gov/pmc/articles/PMC3680175/ (Access: 2013.06.20)

²⁴² van Weert JC, van Dulmen AM, Spreeuwenberg PM, Bensing JM, Ribbe MW. The effects of implementation of snoezelen on the quality of working life in psychogeriatric care. Int Psychogeriatr. 2005 Sep;17(3):407-27.

Methods of care of patients affected by dementia

4.1. Institutional care

There are two different systems of taking care of people affected by dementia in Poland: The Ministry of Health and the Ministry of Public Welfare. Elderly patients have access to care services however, there are no services specifically for patients suffering from dementia. The care for patients with dementia is provided by nursing homes, care and treatment centres, nursing-care centres, twenty-four hour and daytime psychogeriatric units, municipal social welfare centres and private nursing homes. A patient's family can also use the services of a respite carer, who looks after the patient at home. It is possible to hire a substitute carer who deals with patients at home. Clinics, Alzheimer's associations and support groups also provide assistance in the provision of care²⁴³.

4.1.2. Nursing Homes

Sick and disabled elderly people who require assistance with living on an everyday basis are provided with twenty-four-hour care in nursing homes. Such homes provide accommodation, caregiving, and educational services, as well as standard assistance depending on the individual needs of the residents. They also provide care services and specialised care services for people who do not live there. Care services include assistance with performing basic everyday activities, assisting with personal issues, nursing and hygienic care of patients, organization of their leisure time and contact with their immediate environment²⁴⁴.

In 2011 in Poznań there were seven nursing homes, four of which were run by the city and three by religious organisations, which provided a total of 716 places²⁴⁵.

²⁴³ Durda M., Organizacja opieki nad osobami z demencją w Polsce na tle krajów rozwiniętych i rozwijających się, [The organization of care for people with dementia in Poland in the context of developed and developing countries], "Gerontologia Polska" 2010, vol. 18, no 2, p. 77.

²⁴⁴ Ustawa z dnia 12 marca 2004 r. o pomocy społecznej [The Act of 12 March 2004 on social assistance], Dziennik Ustaw [Journal of Laws] 2004 no 64 item 593.

²⁴⁵ Miejskie jednostki organizacyjne pomocy społecznej [Municipal social welfare organisational units], Urząd Miasta Poznania [Poznan City Council] 2012, p. 66.

In 2011, 280 people were placed in nursing homes, that is, 160 in Poznań and 120 in surrounding areas. At the same time, there were 528 people waiting to be placed, which amounted to 136 people more than in 2010²⁴⁶ (table 17).

Table 17. The list of municipal social welfare homes in Poznan, including the number of places and division by type (as of 31.12.2011).

No.	Social welfare home description	Type of home	Number of places
1	Konarskiego St. 11/13 (+ branch Zamenhofa St.)	For people with chronic somatic diseases (M+W)	170
2	Niedziałkowskiego St. 22	For people with chronic somatic diseases (W)	35
3	Bukowska St. 27/29	For the elderly (M+W)	140
4	Ugory St. 20	For the elderly and the physically disabled (M+W)	136 (including 116 for the elderly and 20 for the physically disabled)
Total	481		

Source: Municipal social welfare provision units, Poznań City Council 2012, p. 66.

Table 18. The list of private nursing homes in Poznan including the name of the institution, number of places and division by type of home (as of 31.12.2011).

	Nursing Home description	Institution running the home	Type of home	Number of places
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²⁴⁶ Miejskie jednostki organizacyjne pomocy społecznej [Municipal social welfare organisational units], Urząd Miasta Poznania [Poznan City Council] 2012, p.50.

1	Pokrzywno St. 1	Congregation of the Ursulines	For the elderly (W)	35
2	Św. Rocha St. 13	Congregation of the 'Serafitki' sisters	For children and young people with learning disabilities (56 places for girls, 4 for boys)	60
3	Sielska St. 13 (together with a branch at Mińska St. 17)	Daughters of Charity of Saint Vincent de Paul	For people with chronic somatic diseases (W)	140 (including Minska St. branch - 47)
	Total	235		

Source: Municipal social welfare provision units, Poznań City Council 2012, p. 66-67.

Among the residents, a majority are aged over 74 and they amount to 61% of all residents. Residents between 61-74 years old are the next big group and they constitute 20% of residents. 81% of people in nursing homes are over 60 years old with ability limited because of age, and finally, 28% of people are bed-ridden²⁴⁷.

Medical care is administered by General Practitioners via contracts with the National Health Fund. Residents are offered advice in consulting rooms based in nursing homes or outside the institution. Nursing homes also provide access to specialists if residents need a consultation or specialised tests²⁴⁸.

²⁴⁷ Miejskie jednostki organizacyjne pomocy społecznej [Municipal social welfare organisational units], Urząd Miasta Poznania [Poznan City Council] 2012, p. 68.

²⁴⁸ Miejskie jednostki organizacyjne pomocy społecznej [Municipal social welfare organisational units], Urząd Miasta Poznania [Poznan City Council] 2012, p. 69.

Nursing homes offer an opportunity for their residents to participate in recreational and cultural events outside the institution and enable social activity through community centres, senior clubs, schools and kindergartens²⁴⁹.

4.1.4. ‘Day stay’ Branches of Nursing Homes

There are two ‘day stay’ branches of nursing homes in Poznań (Konarskiego St. 11/13 and Bukowska St. 27/29) working since 2000. In 2011 there were 45 places. The homes offered a day stay for people with limited physical ability and provided care as well as educational, recreational and cultural services²⁵⁰.

4.1.3. Care and Treatment Centres

Care and treatment centres offer round the clock medical services for the care and rehabilitation of people who do not require hospitalisation. The centres provide pharmaceuticals, medical supplies, rooms and catering in accordance with the condition of patients, as well as supervision during cultural and recreational activities organised within the centre²⁵¹.

The table below shows the characteristics of the care and treatment centres in the Wielkopolska region in 2009-2011 (table 19).

Table 19 Care and treatment centres in the Wielkopolska region.

Description	2009	2010	2011

²⁴⁹Miejskie jednostki organizacyjne pomocy społecznej [Municipal social welfare organisational units], Urząd Miasta Poznania [Poznan City Council] 2012.

²⁵⁰ Miejskie jednostki organizacyjne pomocy społecznej [Municipal social welfare organisational units], Urząd Miasta Poznania [Poznan City Council] 2012, p.70.

²⁵¹ Ustawa z dnia 30 sierpnia 1991 r. o zakładach opieki zdrowotnej [Act of 30 August 1991 on Health Care Establishments], Dziennik Ustaw [Journal of Laws] 1991 No. 91, item 408.

	Number of entities	Number of places	Number of patients	Number of entities	Number of places	Number of patients	Number of entities	Number of places	Number of patients
Care and treatment centres	14	632	1444	15	794	2015	20	863	2039

Source: Statistical Guide to Healthcare in the Wielkopolska Region 2011, Wielkopolska Public Health Centre, Poznań 2012, p. 169.

4.1.5. Nursing and care centres

Nursing and care centres offer round the clock medical services for the care and rehabilitation of people who do not require hospitalisation. They provide continuity of medical treatment, rooms and catering in accordance with the conditions of the patients, as well as providing health education to patients and their families²⁵².

Table 4 shows the characteristics of the nursing and care centres in the Wielkopolska region in 2009-2011.

Table 20. Nursing and Care centres in the Wielkopolska region.

Description	2009	2010	2011

²⁵² Rozporządzenie Ministra Zdrowia i Opieki Społecznej z dnia 30 grudnia 1998 r. w sprawie sposobu i trybu kierowania osób do zakładów opiekuńczo-leczniczych i pielęgnacyjno opiekuńczych oraz szczegółowych zasad ustalania odpłatności za pobyt w tych zakładach [Decree of the Minister of Health on the course of referring patients to health care and curative institutions and the detailed procedures of determining the cost of their stay of 30 December 1998], Dziennik Ustaw [Journal of Laws] 1998 No. 166 item 1265.

	Number of entities	Number of places	Number of patients	Number of entities	Number of places	Number of patients	Number of entities	Number of places	Number of patients
Care and treatment centres	4	357	554	6	357	625	5	390	610

Source: Informator liczbowy ochrony zdrowia województwa wielkopolskiego – 2011,

[Statistical Guide to Healthcare in the Wielkopolska Region 2011], Wielkopolskie Centrum Zdrowia Publicznego [Wielkopolska Public Health Centre], Poznan 2012, p.169.

4.2. Part-time care

Out-patient care service is often provided by a nurse or carer. The assistance mainly concerns day-to-day care, as well as wound care. In Poland, carers are employed by care agencies which cooperate with social welfare centres. Social organizations, local government and private organizations provide day care. The care provided to the patient during the day significantly relieves the burden on the carer²⁵³.

In 2011 in Poznań care services and specialised care services were offered to 2517 people, including 2027 people living on their own and 490 living with families.

4.3. Home care

Taking care of incapacitated elderly people is one of the duties of the family. It stems from tradition, a sense of duty and gratitude, but also out of necessity, because of the lack of alternative forms of care. Sometimes, instead of spontaneous motives and satisfaction due

²⁵³ Durda M., Organizacja opieki nad osobami z demencją w Polsce na tle krajów rozwiniętych i rozwijających się [The organization of care for people with dementia in Poland in the context of developed and developing countries], „Gerontologia Polska” 2010, vol. 18, no. 2, p. 80.

to overcoming hardships, one experiences helplessness, objection and other negative emotions²⁵⁴.

Access to formal and informal types of assistance is important for supporting carers of people with dementia. The awareness of having additional support often plays a large role and prevents the isolation of carers²⁵⁵. Comprehensive information about the services and facilitates available to the sick, as well as their rights, is extremely important in the initial phase of care. Caregivers need advice on both practical activities involving the provision of care, as well as knowledge related to the course of the disease and the progression of the disability of a family member. Communication with patients, the availability and charges for services, and coping with stress also constitute valuable information. Such support is provided by different kinds of associations and foundations which together provide a comprehensive and reliable source of advice and information²⁵⁶.

4.4. Associations and foundations

Social organizations dealing with the problem of dementia have operated in Poland for several years. They initially used to be established mainly due to the initiative of doctors, but these organizations are now independent from healthcare institutions. In Poznań the following organisations are a great source of knowledge for sufferers and their families:

- **Alzheimer Society of the Wielkopolska region (Wielkopolskie Stowarzyszenie Alzheimerowskie)**

²⁵⁴ Bień B., Wojszel Z. B., Wilmańska J., Sienkiewicz J., Starość pod ochroną. Opiekunowie rodzinni niesprawnych osób starych w Polsce. Porównawcze studium środowiska miejskiego i wiejskiego [Aging protected. Family carers of the old and disabled in Poland. Comparative study of urban and rural environments], Białystok, Kraków 2001, p.110-111.

²⁵⁵ Bień B., Wojszel Z. B., Wilmańska J., Sienkiewicz J., Starość pod ochroną. Opiekunowie rodzinni niesprawnych osób starych w Polsce. Porównawcze studium środowiska miejskiego i wiejskiego [Aging protected. Family carers of the old and disabled in Poland. Comparative study of urban and rural environments], Białystok, Kraków 2001, p. 17.

²⁵⁶ Bień B., Wojszel Z. B., Wilmańska J., Sienkiewicz J., Starość pod ochroną. Opiekunowie rodzinni niesprawnych osób starych w Polsce. Porównawcze studium środowiska miejskiego i wiejskiego [Aging protected. Family carers of the old and disabled in Poland. Comparative study of urban and rural environments], Białystok, Kraków 2001, p. 19.

The organization has been running since 2004 and it provides comprehensive support for patients, their carers and their families. Within the Association there is the **Alzheimer's Disease Information Centre (Ośrodek Informacji Alzheimerowskiej)**, which provides information on the Association's activities and the ways of receiving help. Those interested in obtaining assistance can be provided with specialist help (psychologists, social workers, psychiatrists, therapists and lawyers), as well as participate in support groups led by a psychologist. The **Adaptation and Rehabilitation Centre (Ośrodek Adaptacyjno-Rehabilitacyjny)** and the **Self-Help Home (Środowiskowy Dom Samopomocy)** offer day care, enable participation in activities conducted by psychologists, occupational therapists and physiotherapists²⁵⁷.

- **Wielkopolska Association for People with Alzheimer's Disease (Wielkopolskie Stowarzyszenie na Rzecz Osób z Choro­bą Alzheimer­a)** provides support for people suffering from dementia and their carers, aims to popularise knowledge about Alzheimer's disease and promotes new directions for therapy and diagnosis. The Association runs an information and education centre, as well as providing informational material and professional literature. It also offers various kinds of assistance suffers and their caregivers including: medical, nursing, rehabilitation, care, psychological and legal. It also organises support groups, get-togethers and lectures as well as training for volunteers and carers²⁵⁸.
- **“Flandria” Mutual Aid Association (Stowarzyszenie Wzajemnej Pomocy „Flandria”)** offers nursing home care, advice on the treatment of pain, and dental services refunded by the National Health Fund. It assists in the purchasing and renting of medical supplies necessary for the care of patients²⁵⁹.

²⁵⁷ Poradnik dla opiekunów osób dotkniętych chorobą Alzheimer­a [Guide for caregivers of people with Alzheimer's disease], Wielkopolskie Stowarzyszenie Alzheimerowskie [Wielkopolska Alzheimer Association], Poznan 2008, p. 7.

²⁵⁸ Wielkopolskie Stowarzyszenie na Rzecz Osób z Choro­bą Alzheimer­a [Wielkopolska Alzheimer Association], <http://bazy.ngo.pl/search/info.asp?id=94581>, date of access 4.05.2013

²⁵⁹ Wielkopolskie Stowarzyszenie Alzheimerowskie [Wielkopolska Alzheimer Association], p. 38.

- **“Poznan Seniors” Geriatric and Gerontological Centre** (Ośrodek Geriatryczno-Gerontologiczny „Poznańskie Centrum Seniora”) seeks to improve the quality of life of old people and their families. The centre provides information and advice, specialised medical care, and access to free consultations and medical tests. It has a mobile interdisciplinary team consisting of doctors with various specialties, nurses and psychologists. The Centre provides help to the residents of Poznań, who are at least 60 years old²⁶⁰.

4.4.1 The role of nurses in caring for patients with dementia

Educational activities no always can enable nurses to create a team of carers for patients with cognitive impairment. Based on other disciplines, authors suggest the need to involve cognitive science specialists in care. Stimulating activity of the brain may slow down the process of dementia. In order to stimulate the patient, a cognitive scientist can use all the methods and tools to stimulate the brain and its correct functioning while adjusting the stimulation according to the needs, type and level of a patient’s disorder at a given time. Cognitive scientists also have the tools for a comprehensive assessment of the functional status of the patient.

As their tools, cognitive scientists can use everyday materials, such as games (e.g. popular scrabble), brain teasers, riddles (even the children's ones), puzzles, toys, and other objects. Those activities can result in the decrease in the cost of care in the long run.

Introducing a cognitive scientist to the team would allow for the comprehensive education of caregivers, familiarising them with the symptoms of cognitive impairment in the elderly, with the process of degradation of cognitive processes, prophylactic methods and those preventing the development of cognitive impairments.

²⁶⁰ Poradnia geriatryczna [Geriatric clinic], <http://hospicjum-domowe.com>, date of access 4.05.2013

Authors believe that joining the forces of nurses and cognitive scientists would allow for the effective prevention of caregiver burden, which would bring tangible support to patients and their carers²⁶¹.

Another possibility recognised by authors is the opportunity for nurses to promote educational materials. In the age of mass media, and especially an information platform such as the Internet, it is so easy to pass on educational knowledge with little financial input compared to traditional forms. There is currently research being done on the effectiveness of this technique in the geriatric population of Poland²⁶². Although today many older people cannot use communication and audiovisual equipment this number will grow in time. Also, the number of carers who are acquainted with such methods of obtaining information will grow as well.

We can find examples of forms of education via the Internet in one initiative from the Alzheimer Association, who are engaged in various large-scale educational programmes on a dynamic website. They include e.g. Dementia Care Practice Recommendations created by the Alzheimer Association, which is a unique educational programme for patients and their carers as well as professionals²⁶³. Another example of the use of media such as the Internet for a major educational initiative in the field of dementia (published 22 February 2013) is: What is Dementia - Presented by Dr. David B. Reuben Chief, Geriatric Medicine, UCLA | UCLA Alzheimer's and Dementia Care Program, which is available on YouTube. The programme is a part of Alzheimer's Caregiver Education Lecture Series²⁶⁴. MEDtube is also a well-known online service widely-used at universities during classes with students²⁶⁵.

²⁶¹ Brzezińska A. I., Łazar M., Wójcik S., Wizerunek późnej dorosłości a problemy opieki długoterminowej i wsparcie potrzebne opiekunom [The image of late adulthood. Long-term care problems and support for carers in need], *Gerontol. Pol.* 2011; 19, 3-4: 181-189.

²⁶² Kopaniszyn I. Rola Internetu w rozpowszechnianiu informacji zdrowotnych wśród starszych osób [The role of the Internet in disseminating health information to the elderly]. The analysis of www.senior.pl, *Gerontol. Pol.* 2007; 15, 1-2: 14 – 20.

²⁶³ Dementia Care Practice Recommendations created by Alzheimer Association http://www.alz.org/professionals_and_researchers_dementia_care_practice_recommendations.asp, date of access 25.04.2013.

²⁶⁴ What is Dementia - Presented by Dr. David B. Reuben | UCLA Alzheimer's and Dementia Care Program, <http://www.youtube.com/watch?v=wyO1qQwRHVY>, date of access 19.04.2013

²⁶⁵ <http://medtube.net/>, date of access 27.04.2013

Polish nursing has the opportunity to not only positively impact on the increase of the health of Poles, but also to develop nursing as a scientific discipline and improve itself by engaging in the creation of a system of education of patients with CI. Being open to other fields of science allows for the creation of an effective and interdisciplinary team who would also be joined by caregivers and patients.

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4.4.2. The role of a physiotherapist in the care of patients with dementia

Physiotherapy is a valuable part of treatment people with dementia. The role of physiotherapist among patients with dementia may be divided into two branches: helping to resolve the physical problems and solving the problems related to dementia. It is obvious for generally acknowledge that sometimes those two branches of problems may be connected to each other, for example, falling or pain. Nevertheless, each person with dementia should be treated not only like a patient with physical or neurological deficits but as an unique person. The results of interventions are reducing the impact of

dementia on the person's everyday life and maximize the person's functional potential²⁶⁶.

These are a lot of dysfunctions which develop during dementia. They are related to such aspects as:

- 1) Musculoskeletal
- 2) Mobility
- 3) Pain

Firstly, the most common musculoskeletal disorders are osteoarthritis, muscle weakness, fracture. That is why it is important to apply flexibility exercises for musculoskeletal system with taking into account osteoarthritis and other disorders in skeletal system of patient with dementia. Gentle stretching techniques, joint mobilization to reduce tightness of the joint's capsule or of ligaments, autostretching should be provided by physiotherapists in patients with dementia. Thanks to therapy the patients can improve joints range of motion. However, not only relaxing or stretching treatment should be applied but also strengthening is very important²⁶⁷. Proprioceptive Neuromuscular Facilitation (PNF) is also common way of treatment of patients with dementia. There are some specific techniques such as: Muscle inhibition techniques, Hold Relax or Contract Relax. One of the aims of PNF is to facilitate the functional, everyday movement^{268, 269}. The most common fractures in patients with dementia are hip fractures. Relative to other types of osteoporotic fractures, they result in the longest hospital stays and the highest costs. Patients over 85, are more likely to be dependent on others for activities on daily living. Physical therapy for people with hip fractures is

²⁶⁶ Marshall M. Perspective on Rehabilitation and Dementia. Jessica Kingsley Publishers. London and Philadelphia. 2005

²⁶⁷ Kaur J. Sharma S. Mittal J. Physiotherapy in dementia. Delhi Psychiatry Journal. 15 (1) 2012.

²⁶⁸ Ibidem

²⁶⁹ Marshall M. Perspective on Rehabilitation and Dementia. Jessica Kingsley Publishers. London and Philadelphia. 2005

standard and crucial to their return to their previous dwelling places in the community. Physical therapy immediately after hip fracture surgery is also very important because it is associated with significantly better locomotion at least in months later^{270, 271, 272}. Similarly, after 6 months of extended outpatient rehabilitation that includes progressive resistance training can improve physical function and quality of life and reduce disability. To summarize musculoskeletal problems, the interventions of physical therapists in order to reduce those disorders should included whole-body progressive resistance exercise training, strengthening, “range-of-motion” and stretching exercises and transfer training^{273, 274}.

Second, mobility disorders are associated with physical symptoms such as: rigidity, balance problem, shuffling gait. Those problems lead to difficulties with transfer of the body, for instance: from laying to sitting, from sitting to standing. Physiotherapists may provide specific therapy including special exercises or they provide the patients with a mobility aid: walking sticks, zimmer frame or a rollator²⁷⁵. Rigidity may be treated using musculoskeletal therapy. Body balance and coordination must be improved by physical therapists in order to provide the patient better sense of surrounding space and environment in everyday life. Training should include weight bearing in both sitting and standing position in order to help the patient develop

²⁷⁰ Binder E.F. Brown M. Sinacore D.R. Steger M. K. JAMA. 2004;292:837-846.

²⁷¹ Penrod J.D. Boockvar K.S. Litke A. Hannan E.L. Halm E.A. Silberzweig S.B. Morrison R.S. Orosz G.M. Koval K.J. Siu A.L. Physical Therapy and mobility after 2 and six months after hip fracture. J Am Geriatr Soc. 2004 July; 52(7): 1114–1120.

²⁷² Yeresheki K.E. Schechtman Effects of Extended Outpatient Rehabilitation After Hip Fracture

²⁷³ Allen J. Koziak A. Buddingh S. Liang J. Buckingham J. Beaupre L.A. Rehabilitation in patients with dementia following hip fracture : a systematic review. Physiotherapy Canada 2012; 64(2);190–201.

²⁷⁴ Binder E.F. Brown M. Sinacore D.R. Steger M. K. JAMA. 2004;292:837-846.

²⁷⁵ Marshall M. Perspective on Rehabilitation and Dementia. Jessica Kingsley Publishers. London and Philadelphia. 2005.

stability. Some of the activities applied to patients may include Swiss ball but the most important exercises are those which consider everyday life, for example Kitchen sink exercises: the patient can be instructed heel-toe standing or single limb stance during washing dishes, partial wall squats and chair rises²⁷⁶. Thanks to physiotherapy intervention a patient may improve her/his mobility and independence which play an important role in advising and supporting family to live easier life.

Decreased mobility can be based on unrelieved pain in patients with dementia, especially in persons who have problem with verbal communication. That is why, firstly the pain should be appropriately detected, and later treated. The scale that enable assessing the pain in patients with severe dementia called The Pain Assessment in Advanced Dementia (PAINAD)²⁷⁷. The scale includes five indicators: breathing (labored breathing or hyperventilating), vocalization (moaning or crying), facial expression (frowning or grimacing), body language (clenching fists or pushing away caregivers), and consolability (an inability to be comforted). Physiotherapists observe those five indicators. Each item is scored on a scale of 0 to 2. The more points the patient gets, the more severe the pain is²⁷⁸. There are some non drug intervention for pain, for example Transcutaneous Electrical Nerve Stimulation (TENS), gentle massage or gentle exercises²⁷⁹. What is more, short education program including postural hygiene: the way how to lift object, how to change position in bed, instruction to patients in gait may decrease pain, especially in patients who have low back pain. Living without pain increase the level of physical activity in everyday life²⁸⁰. Pomeroy demonstrated that physiotherapy connected with music and movement therapy in groups, plus body

²⁷⁶ Kaur J. Sharma S. Mittal J. Physiotherapy in dementia. Delhi Psychiatry Journal.15 (1) 2012.

²⁷⁷ Horgas A. Pain Assessment in People with Dementia. AJN.108; (7). 2008.

²⁷⁸ Ibidem.

²⁷⁹ Marshall M. Perspective on Rehabilitation and Dementia. Jessica Kingsley Publishers. London and Philadelphia. 2005.

²⁸⁰ Albaladejo C. Kovacs F.M. Royuela A. Pino R. Zamora J. The Efficacy of a Short Education Program and a Short Physiotherapy Program for Treating Low Back Pain in Primary Care. Spine 2010;35: 483–496.

awareness and functional mobility training, significantly improve the mobility without pain of elderly people with a dementing illness²⁸¹.

Patients with dementia very often suffer from falling. Nashner and Cordo demonstrated that the number of falls associated with ageing was due to decreased muscle strength and flexibility²⁸². That is why physiotherapy should consist of exercises which develop muscular strength, proprioception, static and dynamic balance and flexibility. Regular training with physiotherapist may improve walking, mobility and flexibility, which can reduce falls and help maintain autonomy.

Cognitive function may be mobilized just by attention and language stimulated as Neely and Backman showed ²⁸³. Patients with dementia who regularly take part in physical therapy became enthusiastic during the training sessions. This enthusiasm affects their behaviour: they laugh, and take with pleasure ²⁸⁴.

To summarize, physical exercise with addition of other branches of treatment and stimulation such as mental and social interaction all seem to influence not only physical functions but also the maintenance or progression of cognitive abilities of demented elderly subjects.

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²⁸² Nashner LM, Cordo PJ. Relation of automatic postural responses and reaction-time voluntary movements of human leg muscles. Exp Brain Res 1981; 43: 395–405.

²⁸³ Neely AS, Backman L. Long term maintenance of gains from memory training in older adults: two 3½-year follow up studies. J Gerontol Psychol Sci 1993; 48: 233–7.

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4. Evaluation of the psychophysical functioning of carers

5.1. Introduction

One of the most important changes in the care system is that due to increased life expectancy and the shift from acute to chronic diseases the number of disabled people has increased. Consequently, the number of individuals involved in caregiving, the duration of caregiving role and the types of caregiving tasks performed have also changed as for many caregivers such a role last for many years, even decades and caregiving has become very complex task ²⁸⁵.

5.2. Caregiver burden (CB)

Caregiver burden (CB), also known as caregiver strain or stress ²⁸⁶ is defined as “a multidimensional response to the negative appraisal and perceived stress resulting from taking care of an ill individual”. It threatens with physical, psychological, emotional and functional health of caregivers^{287, 288, 289} and create financial burden ²⁹⁰. What is important is that CB also affects further decline in cognitive, functional and neuropsychiatric

²⁸⁵ Schulz R., Martire L.M. (2004). Family caregiving of persons with dementia. Prevalence, health effects, and support strategies. *American Journal of Geriatric Psychiatry* 12(3): 240-249.

²⁸⁶ Nguyen M. (2009). Nurse's assessment of caregiver burden, *Medsurd Nursing* 18(3): 147-151.

²⁸⁷ Etters L., Goodall D., Harrison B.E. (2008). *Caregiver* burden among dementia patient caregivers: a review of the literature. *Journal of American Academy of Nurse Practitioners* 20(8): 423-428.

²⁸⁸ Carretero S., Garcés J., Ródenas F., Sanjosé V. (2009) The informal caregiver's burden of dependent people: theory and empirical review. *Archives of Gerontology and Geriatrics* 49(1):74-79.

²⁸⁹ Kim H., Chang M., Rose K., Kim S. (2012). Predictors of caregiver burden in caregivers of individuals with dementia. *Journal of Advanced Nursing* 68(4): 846-855.

²⁹⁰ Connell C.M., Janevic M.R., Gallant M.P. (2001), The costs of caring: impact of dementia on family caregivers. *Journal of Geriatric Psychiatry and Neurology* 14(4): 179-187.

problems of dementia patients ²⁹¹, ²⁹² point to the reciprocal impact that dementia patient and caregiver have on each other, as the care-recipient state affects caregiver burden in both objective and subjective terms, and this may lead to a worsening of care and undermine quality of life of both caregiver and dementia patient ²⁹³, ²⁹⁴. Degree of CB depends on various contextual factors, caregiving-related factors and primary stressors including socio-demographical status of caregivers and caretakers, disease progression and perceived stress ²⁹⁵, ²⁹⁶, ²⁹⁷, ²⁹⁸. Care-recipient factors are the most important no matter whether it was related to decreased ADL or IADL ²⁹⁹, ³⁰⁰. What is important, is that a caregiver's perception of the severity of the symptoms may be more important to consider

²⁹¹ Dang S., Badiye A., Kelkar G. (2008). The dementia caregiver – a primary care approach. *South Medical Journal* 101(12): 1246-1251.

²⁹² Schulz R., Martire L.M. (2004). Family caregiving of persons with dementia. Prevalence, health effects, and support strategies. *American Journal of Geriatric Psychiatry* 12(3): 240-249.

²⁹³ Balducci C., Melchiorre M.G., Quattrini S., Lamura G. (2008). Caring for a family member with dementia: evidence from a cross sectional comparative study on caregiver burden and psychological well-being. *European Papers on the New Welfare* 9: 182-197.

²⁹⁴ Bruvik F.K., Ulstein I.D., Ranhoff A.H., Engedal K. (2012). *The quality of life of people with dementia and their family carers*. *Dementia and Geriatric Cognitive Disorders* 34(1): 7-14.

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²⁹⁹ Conde-Sala J.L., Garre-Olmo J., Turró-Garriga O., Vilalta-Franch J., López-Pousa S. (2010). Differential features of burden between spouse and adult-child caregivers of patients with Alzheimer's disease: an exploratory comparative design. *International Journal of Nursing Studies* 47(10): 1262-1273.

³⁰⁰ Kim H., Chang M., Rose K., Kim S. (2012). Predictors of caregiver burden in caregivers of individuals with dementia. *Journal of Advanced Nursing* 68(4): 846-855.

than the actual problem behavior itself. CB includes both objective and subjective dimension of caring. The former includes time and energy spent on physical aspects of caregiving that may be unfamiliar or unpleasant, such as feeding, bathing, clothing and assisting with toileting ^{301, 302, 303, 304} and the latter refers to caregiver's experience of burden, e.g. his or her perception and emotional reactions to caregiving ^{305, 306}. Additionally, caregivers who are advanced in age, women ³⁰⁷, live together with dementia patients are more prone to experience CB than young, male caregivers who do not live with

³⁰¹ Balducci C., Melchiorre M.G., Quattrini S., Lamura G. (2008). Caring for a family member with dementia: evidence from a cross sectional comparative study on caregiver burden and psychological well-being. *European Papers on the New Welfare* 9: 182-197.

³⁰² Brodaty H., Donkin M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience* 11(2): 217-228.

³⁰³ Connell C.M., Janevic M.R., Gallant M.P. (2001). The costs of caring: impact of dementia on family caregivers. *Journal of Geriatric Psychiatry and Neurology* 14(4): 179-187.

³⁰⁴ Schulz R., Martire L.M. (2004). Family caregiving of persons with dementia. Prevalence, health effects, and support strategies. *American Journal of Geriatric Psychiatry* 12(3): 240-249.

³⁰⁴ Kim H., Chang M., Rose K., Kim S. (2012). Predictors of caregiver burden in caregivers of individuals with dementia. *Journal of Advanced Nursing* 68(4): 846-855.

³⁰⁵ Nguyen M. (2009). Nurse's assessment of caregiver burden, *Medsurg Nursing* 18(3): 147-151.

³⁰⁶ Tremont G. (2011). Family Caregiving in Dementia, *Medicine and Health/Rhode Island* 94(2): 36-38.

³⁰⁷ Papastavrou E., Kalokerinou A., Papacostas S., Tsangari H., Sourtzi P. (2007). Caring for a relative with dementia: Family caregiver burden. *Journal of Advanced Nursing* 58(5): 446-457.

PWD^{308, 309, 310}. Spouses and daughters of PWD express the highest level of burden^{311, 312}. Moreover, Etters et al (2008) observe that while females report CB in their relationships with other family members and increased health problems, males experience lack of positive outcomes and the need for social support. For that reason, there are found gender differences in coping strategies: while female focus on emotion-focused coping males are more focused on problem-solving strategies. Caucasian caregivers are at greater risk of CB than African and Latinos³¹³.

Most authors lists four major consequences of caregiving for dementia patient: physical, social, financial, psychological.

5.2.1. Physical consequences

Decline in health. CB may result in decline in both physical and mental health. Caregivers of dementia patient (DP) are at risk of higher morbidity, including hypertension, Rheumatoid arthritis and possibly cancer³¹⁴. CB causes cardiovascular

³⁰⁸ Conde-Sala J.L., Garre-Olmo J., Turró-Garriga O., Vilalta-Franch J., López-Pousa S. (2010). Differential features of burden between spouse and adult-child caregivers of patients with Alzheimer's disease: an exploratory comparative design. *International Journal of Nursing Studies* 47(10): 1262-1273.

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³¹¹ Andren S. and Elmstahl S. (2008). The relationship between caregiver burden, caregivers' perceived health and their sense of coherence in caring for elders with dementia. *Journal of Clinical Nursing* 17(6): 790-799.

³¹² Etters L., Goodall D., Harrison B.E. (2008). Caregiver burden among dementia patient caregivers: a review of the literature. *Journal of American Academy of Nurse Practitioners* 20(8): 423-428.

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problems, lower immunity, poorer response to vaccine, slower wound healing, higher level of chronic conditions (diabetes, arthritis, ulcers and anemia) ³¹⁵. Additionally, caregivers of DP have higher diastolic blood pressure, higher noradrenaline levels and lower cell-mediated immunity ³¹⁶. They have more visits to doctors than non-caregivers and use more prescribed medications^{317, 318, 319, 320} have poorer self-related health, decreased engagement in preventive behaviors, poor diets and greater likelihood of smoking, drinking alcohol and poor patterns of sleep related to constant thinking and

³¹⁵ Brodaty H., Donkin M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience* 11(2): 217-228.

³¹⁶ Dang S., Badiye A., Kelkar G. (2008). The dementia caregiver – a primary care approach. *South Medical Journal* 101(12): 1246-1251.

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preoccupation about the one's future and that of the dementia patient^{321, 322, 323, 324, 325}. CB resulting from primary caregiving role is also an independent risk factor for higher mortality rate³²⁶.

Decreased quality of life (QoL). Caregivers feel concerned about their quality of life (QoL)^{327, 328, 329}. Although QoL of the carers is better than that of PWD, carers living with dementia patients have lower QoL than both those who live in another household and carers of nondementia patients³³⁰.

5.2.2. Financial consequences

³²¹ Brodaty H., Donkin M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience* 11(2): 217-228.

³²² Galvin J.E., Duda J.E., Kaufer D.I., Lippa C.F., Taylor A., Zarit S.H. (2010). Lewy body dementia: caregiver burden and unmet needs. *Alzheimer Disease and Associated Disorders* 24(2): 177-181.

³²³ McCurry S.M., Logsdon R.G., Teri L., Vitiello M.V. (2007). Sleep disturbances in caregivers of persons with dementia: contributing factors and treatment principles. *Sleep Medicine Reviews* 11(2): 143-153.

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Financial stress. Wimo and collaborators³³¹ distinguish direct medical cost and direct social care costs. The former include medical care system, such as costs of hospital care, medical consultation and visits to clinics, pharmaceuticals and provision of personal and nursing care, including residential³³². Indirect costs are much harder to assess, as they include the value of caregiving time, the caregiver's lost income and earnings, out-of-pocket expenses for formal caregiving services, and the caregiver's excess health costs. It also include services provided outside the medical care system, such as home visits, food supply, transport and residential or nursing home care.

Problems with employment. Caregivers of DP report more work-related difficulties, including missing work, being tired at work, missing new job opportunities or chances of promotion. They face opposition from employers which often force scarification of job. According to Dang at al.^{333, 334, 335, 336} about 50% of caregivers decrease

³³¹ Wimo A., Jönsson L., Bond J., Prince M., Winblad B. (2013). The worldwide economic impact of dementia, *Alzheimer's & Dementia* 9(1): 1-11.

³³² Brodaty H., Donkin M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience* 11(2): 217-228.

³³³ Dang S., Badiye A., Kelkar G. (2008). The dementia caregiver – a primary care approach. *South Medical Journal* 101(12): 1246-1251.

³³⁴ Bosanquet N. (2001) Socioeconomic impact of Alzheimer's disease. *International Journal of Geriatric Psychiatry* 16(3): 249-253

³³⁵ Brodaty H., Donkin M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience* 11(2): 217-228.

³³⁶ Connell C.M., Janevic M.R., Gallant M.P. (2001), The costs of caring: impact of dementia on family caregivers. *Journal of Geriatric Psychiatry and Neurology* 14(4): 179-187.

their work hours and 18% quit jobs. Furthermore, for many caregivers, especially those in the young age, taking care of DP is only one of many financial responsibilities^{337, 338, 339}.

Lack of environmental tools to manage care. Another problem is related to the lack of financial resources necessary to make environmental changes in the home, such as assistive devices in the bathroom, special locks on outside doors^{340, 341}. It makes caregivers overload and physically exhausted with such tasks as moving the patient, dressing, changing dippers.

5.2.3. Psychological consequences

Depression. Caregiving to dementia patients is more stressful than care for other disabled persons or the elderly in general^{342, 343, 344}. Researches show strong correlation

³³⁷ Bosanquet N. (2001) Socioeconomic impact of Alzheimer's disease. *International Journal of Geriatric Psychiatry* 16(3): 249-253.

³³⁸ Brodaty H., Donkin M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience* 11(2): 217-228.

³³⁹ Connell C.M., Janevic M.R., Gallant M.P. (2001), The costs of caring: impact of dementia on family caregivers. *Journal of Geriatric Psychiatry and Neurology* 14(4): 179-187.

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³⁴¹ Gaugler J.E., Anderson K.A., Leach M.S., Smith C.D., Schmitt F.A, Mendiondo M. (2004). The emotional ramifications of unmet need in dementia caregiving. *American Journal of Alzheimer's Disease & Other Dementias* 19(6): 369-380.

³⁴² Brodaty H., Donkin M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience* 11(2): 217-228.

³⁴³ Ryan K.A., Weldon A., Persad C., Heidebrink J.L., Barbas N., Giordani B. (2012). Neuropsychiatric symptoms and executive functioning in patients with mild cognitive impairment: relationship to caregiver burden. *Dementia and Geriatric Cognitive Disorders* 34(3-4): 206-215.

³⁴⁴ Tremont G. (2011). Family Caregiving in Dementia, *Medicine and Health/Rhode Island* 94(2): 36-38.

between family caregiving, CB and psychological morbidity including depression and anxiety. Rates of depression vary between 23% and 85% in developed countries and of anxiety between 16% and 45%. In those countries psychiatric morbidity range from 40% to 75%^{345, 346, 347, 348, 349}: Caregivers depression results from mood changes that are caused by the stress. It is characterized by feeling of fear and sadness, irritability, anger, loneliness, isolation, fatigue, problems with sleeping, including insomnia

³⁴⁵ Balducci C., Melchiorre M.G., Quattrini S., Lamura G. (2008). Caring for a family member with dementia: evidence from a cross sectional comparative study on caregiver burden and psychological well-being. *European Papers on the New Welfare* 9: 182-197.

³⁴⁶ Brodaty H., Donkin M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience* 11(2): 217-228.

³⁴⁸ Ryan K.A., Weldon A., Persad C., Heidebrink J.L., Barbas N., Giordani B. (2012). Neuropsychiatric symptoms and executive functioning in patients with mild cognitive impairment: relationship to caregiver burden. *Dementia and Geriatric Cognitive Disorders* 34(3-4): 206-215.

³⁴⁹ Schulz R., Beach S.R. (1999). Caregiving as a risk factor for mortality. The caregiver health effects study. *Journal of the American Medical Association* 282(23): 2215-2219.

³⁵⁰, ³⁵¹, ³⁵², ³⁵³, ³⁵⁴, ³⁵⁵, ³⁵⁶, ³⁵⁷, ³⁵⁸. Factors that affect the risk of depression include the number, severity and longitude of symptoms, type and number of caregiving tasks, duration of caregiving, patient's behavioral problems, family conflicts and lack of financial and social support. Except of high incidence of depression caregivers experience anxiety and psychiatric drug use. They have poorer perceiver health statu³⁵⁹. Among factors that predict caregivers depression are younger age (as the caregiving process time is longer), being female spouse or a daughter and being a caregiver of a patient aggressive behavior

³⁵⁰ Alspaugh M.E., Stephens M.A., Townsend A.L., Zarit S.H., Greene R. (1999). Longitudinal patterns of risk for depression in dementia caregivers: objective and subjective primary stress as predictors. *Psychology and Aging* 14(1): 34-43.

³⁵¹ Bruvik F.K., Ulstein I.D., Ranhoff A.H., Engedal K. (2012). The quality of life of people with dementia and their family carers. *Dementia and Geriatric Cognitive Disorders* 34(1): 7-14.

³⁵² Cuijpers P. (2009). Depressive disorders in caregivers of dementia patients: a systematic review. *Aging Mental Health* 9(4): 325-230.

³⁵³ Etters L., Goodall D., Harrison B.E. (2008). Caregiver burden among dementia patient caregivers: a review of the literature. *Journal of American Academy of Nurse Practicioners* 20(8): 423-428.

³⁵⁴ Galvin J.E., Duda J.E., Kaufer D.I., Lippa C.F., Taylor A., Zarit SH. (2010). Lewy body dementia: caregiver burden and unmet needs. *Alzheimer Disease and Associated Disorders* 24(2): 177-181.

³⁵⁵ Lauriks S., Reinersmann A., van der Roest H.G., Meiland F.J., Davies R.J., Moelaert F., Mulvenna M.D., Nugent C.D., Dröes R.M. (2007) Review of ICT-based services for identified unmet needs in people with dementia. *Ageing Research Reviews* 6(3): 223-246.

³⁵⁶ Levine C. (2003) Depression in caregivers of patients with dementia. A greater role for physicians. *Journal of General Internal Medicine* 18(12): 1058-1059.

³⁵⁷ McCurry S.M., Logsdon R.G., Teri L., Vitiello M.V. (2007). Sleep disturbances in caregivers of persons with dementia: contributing factors and treatment principles. *Sleep Medicine Reviews* 11(2): 143-153.

³⁵⁸ Nguyen M. (2009). Nurse's assessment of caregiver burden, *Medsurd Nursing* 18(3): 147-151.

³⁵⁹ Dang S., Badiye A., Kelkar G. (2008). The dementia caregiver – a primary care approach. *South Medical Journal* 101(12): 1246-1251.

or one who needs assistance in many ADLs, being white, having less education and low income^{360, 361, 362, 363, 364, 365, 366}.

Feeling of isolation. Family caregivers report loss of contact with other family members and friends^{367, 368, 369}. Lack of social contact and support results in feeling of

³⁶⁰ Connell C.M., Janevic M.R., Gallant M.P. (2001), The costs of caring: impact of dementia on family caregivers. *Journal of Geriatric Psychiatry and Neurology* 14(4): 179-187.

³⁶¹ Commissaris C.J., Jolles J., Verhey F.R. Jr., Kok G.J. (1995). Problems of caregiving spouses of patients with dementia. *Patient Education and Counseling* 25(2): 143-149.

³⁶² Leggett A., Zarit S., Taylor A., Galvin J. (2010). Stress and burden among caregivers of patients with Lewy body dementia. *The Gerontologist* 51(1): 76-85.

³⁶³ Levine C. (2003) Depression in caregivers of patients with dementia. A greater role for physicians. *Journal of General Internal Medicine* 18(12): 1058-1059.

³⁶⁴ Papastavrou E., Kalokerinou A., Papacostas S., Tsangari H., Sourtzi P. (2007). Caring for a relative with dementia: Family caregiver burden. *Journal of Advanced Nursing* 58(5): 446-457.

³⁶⁵ Schulz R., Beach S.R. (1999). Caregiving as a risk factor for mortality. The caregiver health effects study. *Journal of the American Medical Association* 282(23): 2215-2219.

³⁶⁶ Tremont G. (2011). Family Caregiving in Dementia, *Medicine and Health/Rhode Island* 94(2): 36-38.

³⁶⁷ Andren S. and Elmstahl S. (2008). The relationship between caregiver burden, caregivers' perceived health and their sense of coherence in caring for elders with dementia. *Journal of Clinical Nursing* 17(6): 790-799.

³⁶⁸ Commissaris C.J., Jolles J., Verhey F.R. Jr., Kok G.J. (1995). Problems of caregiving spouses of patients with dementia. *Patient Education and Counseling* 25(2): 143-149.

³⁶⁹ Leggett A., Zarit S., Taylor A., Galvin J. (2010). Stress and burden among caregivers of patients with Lewy body dementia. *The Gerontologist* 51(1): 76-85.

loneliness and isolation^{370, 371, 372, 373, 374}. The risk of social isolation is increased in late stages of dementia³⁷⁵.

Dementia patient's disturbing behaviors and changes in their personality.

Caregivers have problems dealing with changes in the behaviors of DP, especially their decreased cognitive abilities, impulsiveness and aggression, agitation, hyper-sexuality, increased nighttime activity including night wandering, delusions and hallucinations,

³⁷⁰ Brodaty H., Donkin M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience* 11(2): 217-228.

³⁷¹ Commissaris C.J., Jolles J., Verhey F.R. Jr., Kok G.J. (1995). Problems of caregiving spouses of patients with dementia. *Patient Education and Counseling* 25(2): 143-149.

³⁷² Dang S., Badiye A., Kelkar G. (2008). The dementia caregiver – a primary care approach. *South Medical Journal* 101(12): 1246-1251.

³⁷³ Galvin J.E., Duda J.E., Kaufer D.I., Lippa C.F., Taylor A., Zarit S.H. (2010). Lewy body dementia: caregiver burden and unmet needs. *Alzheimer Disease and Associated Disorders* 24(2): 177-181.

³⁷⁴ Lauriks S., Reinersmann A., van der Roest H.G., Meiland F.J., Davies R.J., Moelaert F., Mulvenna M.D., Nugent C.D., Dröes R.M. (2007) Review of ICT-based services for identified unmet needs in people with dementia. *Ageing Research Reviews* 6(3): 223-246.

³⁷⁵ Zwaanswijk M., Peeters J.M., van Beek A.P., Meerveld J.H.C.M., Francke A.L. (2013). Informal caregivers of people with dementia: problems, needs and support in the initial stage and in subsequent stages of dementia: a questionnaire survey. *The Open Nursing Journal* 7: 6-13.

immobility, incontinence, difficulty in walking^{376, 377, 378, 379, 380, 381}. Consequently, caregivers worry that such behaviors may cause unsafe situations in or around the house³⁸²

³⁷⁶ Yeaworth R. and Burke W. (2000). Frontal temporal dementia: A different kind of dementia. *Archives of Psychiatric Nursing* 14(5): 249-253.

³⁷⁷ Etters L., Goodall D., Harrison B.E. (2008). Caregiver burden among dementia patient caregivers: a review of the literature. *Journal of American Academy of Nurse Practitioners* 20(8): 423-428.

³⁷⁸ Gaugler J.E., Anderson K.A., Leach M.S., Smith C.D., Schmitt F.A, Menciondo M. (2004). The emotional ramifications of unmet need in dementia caregiving. *American Journal of Alzheimer's Disease & Other Dementias* 19(6): 369-380.

³⁷⁹ Lauriks S., Reinersmann A., van der Roest H.G., Meiland F.J., Davies R.J., Moelaert F., Mulvenna M.D., Nugent C.D., Dröes R.M. (2007) Review of ICT-based services for Brodaty H., Donkin M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience* 11(2): 217-228.

³⁷⁹ Commissaris C.J., Jolles J., Verhey F.R. Jr., Kok G.J. (1995). Problems of caregiving spouses of patients with dementia. *Patient Education and Counseling* 25(2): 143-149.

³⁷⁹ Dang S., Badiye A., Kelkar G. (2008). The dementia caregiver – a primary care approach. *South Medical Journal* 101(12): 1246-1251.

³⁷⁹ Galvin J.E., Duda J.E., Kaufer D.I., Lippa C.F., Taylor A., Zarit SH. (2010). Lewy body dementia: caregiver burden and unmet needs. *Alzheimer Disease and Associated Disorders* 24(2): 177-181.

³⁷⁹ Lauriks S., Reinersmann A., van der Roest H.G., Meiland F.J., Davies R.J., Moelaert F., Mulvenna M.D., Nugent C.D., Dröes R.M. (2007) Review of ICT-based services for identified unmet needs in people with dementia. *Ageing Research Reviews* 6(3): 223-246.

³⁷⁹ Zwaanswijk M., Peeters J.M., van Beek A.P., Meerveld J.H.C.M., Francke A.L. (2013). Informal caregivers of people with dementia: problems, needs and support in the initial stage and in subsequent stages of dementia: a questionnaire survey. *The Open Nursing Journal* 7: 6-13.

³⁷⁹ Yeaworth R. and Burke W. (2000). Frontal temporal dementia: A different kind of dementia. *Archives of Psychiatric Nursing* 14(5): 249-253.

³⁷⁹ Etters L., Goodall D., Harrison B.E. (2008). Caregiver burden among dementia patient caregivers: a review of the literature. *Journal of American Academy of Nurse Practitioners* 20(8): 423-428.

. According to some researches behavioral disturbances, psychotic symptoms and emotional liability are more troubling than the number of hours spent of care or decline in ADL and IADL^{383, 384, 385} as they cause problems in communication with the patient³⁸⁶. Moreover, such behavioral increase the risk of institutionalization³⁸⁷.

³⁷⁹ Gaugler J.E., Anderson K.A., Leach M.S., Smith C.D., Schmitt F.A, Menciondo M. (2004). The emotional ramifications of unmet need in dementia caregiving. *American Journal of Alzheimer's Disease & Other Dementias* 19(6): 369-380.

³⁷⁹ Lauriks S., Reinersmann A., van der Roest H.G., Meiland F.J., Davies R.J., Moelaert F., Mulvenna M.D., Nugent C.D., Dröes R.M. (2007) Review of ICT-based services for identified unmet needs in people with dementia. *Ageing Research Reviews* 6(3): 223-246.

³⁸⁰ Roopalekha J., Latha K.S., Bhandary P.V. (2010). Burden and coping in informal caregivers of persons with dementia: a cross sectional study. *Online Journal of Health and Allied Sciences* 9(4): 1-6.

³⁸¹ Ryan K.A., Weldon A., Persad C., Heidebrink J.L., Barbas N., Giordani B. (2012). Neuropsychiatric symptoms and executive functioning in patients with mild cognitive impairment: relationship to caregiver burden. *Dementia and Geriatric Cognitive Disorders* 34(3-4): 206-215.

³⁸² Lauriks S., Reinersmann A., van der Roest H.G., Meiland F.J., Davies R.J., Moelaert F., Mulvenna M.D., Nugent C.D., Dröes R.M. (2007) Review of ICT-based services for identified unmet needs in people with dementia. *Ageing Research Reviews* 6(3): 223-246.

³⁸³ Dang S., Badiye A., Kelkar G. (2008). The dementia caregiver – a primary care approach. *South Medical Journal* 101(12): 1246-1251.

³⁸⁴ Schulz R., Beach S.R. (1999). Caregiving as a risk factor for mortality. The caregiver health effects study. *Journal of the American Medical Association* 282(23): 2215-2219.

³⁸⁵ Wimo A., Jönsson L., Bond J., Prince M., Winblad B. (2013). The worldwide economic impact of dementia, *Alzheimer's & Dementia* 9(1): 1-11.

³⁸⁶ Commissaris C.J., Jolles J., Verhey F.R. Jr., Kok G.J. (1995). Problems of caregiving spouses of patients with dementia. *Patient Education and Counseling* 25(2): 143-149.

³⁸⁷ Thomas P., Ingrand P., Lalloue F., Hazif-Thomas C., Billon R., Viéban F., Clément J.-P. (2004). Reasons of informal caregivers for institutionalizing dementia patients previously living at home: the Pixel study, *International Journal of Geriatric Psychiatry* 19(2): 127-135.

Relationship adjustments: alternation of family's past relationship and role reversal. Psychological and behavioral changes affect changes in family roles³⁸⁸. Caregivers are anxious about the fact that the care recipient is no longer able to complete tasks. Role reversal from spouse or child to caregiver is distressing for many caregivers³⁸⁹.

Role ambiguity, discontinuity or insufficiency. As for many caregivers tasks related to caregiving are new they often feel as not prepared or inexperienced for such a new role, especially that many aspects of such a role are unclear for them ³⁹⁰, ³⁹¹, ³⁹², ³⁹³. As they have to take responsibility for the things they were never responsible i.e. management of financial issues, specific household duties, driving or talking to physicians they may

³⁸⁸ de Vugt M.E., Stevens F., Aalten P., Lousberg R., Jaspers N., Verhey F.R. (2005). A prospective study of the effects of behavioral symptoms on the institutionalization of patients with dementia. *International Psychogeriatrics* 17(4): 577-589.

³⁸⁹ Holley C., Mast B. (2009). The impact of anticipatory grief of caregiver burden in dementia caregivers. *The Gerontologist* 49(3): 388-396.

³⁹⁰ Brodaty H., Donkin M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience* 11(2): 217-228.

³⁹¹ Lauriks S., Reinersmann A., van der Roest H.G., Meiland F.J., Davies R.J., Moelaert F., Mulvenna M.D., Nugent C.D., Dröes R.M. (2007) Review of ICT-based services for identified unmet needs in people with dementia. *Ageing Research Reviews* 6(3): 223-246.

³⁹² Nguyen M. (2009). Nurse's assessment of caregiver burden, *Medsurd Nursing* 18(3): 147-151.

³⁹³ Ryan K.A., Weldon A., Persad C., Heidebrink J.L., Barbas N., Giordani B. (2012). Neuropsychiatric symptoms and executive functioning in patients with mild cognitive impairment: relationship to caregiver burden. *Dementia and Geriatric Cognitive Disorders* 34(3-4): 206-215.

experience role insufficiency. Many daily life activities, such as feeding, bathing, clothing and assisting with toileting and taking medications are also disturbing^{394, 395, 396}.

Role overload. As caregiving for DP puts on caregivers cumulative demands of numerous roles, such as spouse, child and employee it is emotionally and physically demanding³⁹⁷. The multitude of roles leads to the feeling of being overwhelmed and being unable to cope with all of those demands^{398, 399, 400, 401}. Feeling of being overload causes

³⁹⁴ Brodaty H., Donkin M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience* 11(2): 217-228.

³⁹⁵ Lauriks S., Reinersmann A., van der Roest H.G., Meiland F.J., Davies R.J., Moelaert F., Mulvenna M.D., Nugent C.D., Dröes R.M. (2007) Review of ICT-based services for identified unmet needs in people with dementia. *Ageing Research Reviews* 6(3): 223-246.

³⁹⁶ Kurz A., Schulz M., Reed P., Wortmann M., Rodrigo J., von Lützu Hohlbein H., Grossberg G. (2008). Personal perspectives of persons with Alzheimer's disease and their carers: a global survey. *Alzheimer's and Dementia* 4(5): 345-352.

³⁹⁷ Zwaanswijk M., Peeters J.M., van Beek A.P., Meerveld J.H.C.M., Francke A.L. (2013). Informal caregivers of people with dementia: problems, needs and support in the initial stage and in subsequent stages of dementia: a questionnaire survey. *The Open Nursing Journal* 7: 6-13.

³⁹⁸ Alspaugh M.E., Stephens M.A., Townsend A.L., Zarit S.H., Greene R. (1999). Longitudinal patterns of risk for depression in dementia caregivers: objective and subjective primary stress as predictors. *Psychology and Aging* 14(1): 34-43.

³⁹⁹ Brodaty H., Donkin M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience* 11(2): 217-228.

⁴⁰⁰ Connell C.M., Janevic M.R., Gallant M.P. (2001), The costs of caring: impact of dementia on family caregivers. *Journal of Geriatric Psychiatry and Neurology* 14(4): 179-187.

⁴⁰¹ Lauriks S., Reinersmann A., van der Roest H.G., Meiland F.J., Davies R.J., Moelaert F., Mulvenna M.D., Nugent C.D., Dröes R.M. (2007) Review of ICT-based services for identified unmet needs in people with dementia. *Ageing Research Reviews* 6(3): 223-246.

sleep disturbance, depression, physical strain and health problems. It also increases the likelihood of institutionalization^{402, 403}

Role captivity. Feeling of being overload may further lead to role captivity as some caregivers feel trapped by the role they do not want be in. Both feeling increase feeling of powerlessness, strain and lose one's sense of self^{404, 405}. According to Thomas et al. (2004) especially, young caregivers who are children of dementia patients are prone to role captivity⁴⁰⁶. It is also affected by the type and stage of dementia, numbers of hours devoted on caring and years spent with the care recipient and tasks involved in caring^{407, 408}. Role captivity increases the feeling of being on one's own in caring and that of lacking both informal and formal support. Consequently, caregivers feel anger and frustration with themselves or care recipient . They also feel ashamed, fatigued and

⁴⁰² McCurry S.M., Logsdon R.G., Teri L., Vitiello M.V. (2007). Sleep disturbances in caregivers of persons with dementia: contributing factors and treatment principles. *Sleep Medicine Reviews* 11(2): 143-153.

⁴⁰³ Spillman B., Long S. (2009). Does high caregiver stress predict nursing home entry. *Inquiry* 46(2):140-161.

⁴⁰⁴ Alspaugh M.E., Stephens M.A., Townsend A.L., Zarit S.H., Greene R. (1999). Longitudinal patterns of risk for depression in dementia caregivers: objective and subjective primary stress as predictors. *Psychology and Aging* 14(1): 34-43.

⁴⁰⁵ Galvin J.E., Duda J.E., Kaufer D.I., Lippa C.F., Taylor A., Zarit S.H. (2010). Lewy body dementia: caregiver burden and unmet needs. *Alzheimer Disease and Associated Disorders* 24(2): 177-181.

⁴⁰⁶ Thomas P., Ingrand P., Lalloue F., Hazif-Thomas C., Billon R., Viéban F., Clément J.-P. (2004). Reasons of informal caregivers for institutionalizing dementia patients previously living at home: the Pixel study, *International Journal of Geriatric Psychiatry* 19(2): 127-135.

⁴⁰⁷ Brodaty H., Donkin M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience* 11(2): 217-228.

⁴⁰⁸ Nguyen M. (2009). Nurse's assessment of caregiver burden, *Medsurg Nursing* 18(3): 147-151.

burnout which are the primary reason for institutionalization^{409, 410}. Role captivity and role overload are two of the most important predictors of CB⁴¹¹.

Problem of being ‘sandwiched’. Caregivers often feel trapped between dual caregiving responsibilities for their children and elderly patients⁴¹². It also refers to a job strain, when a caregiver feels a conflict between the caregiving role and his or her job⁴¹³.

Anticipatory loss and grief. Caregivers worry about deterioration of both physical and mental condition of their relative. They are anxious about changes in their roles, loss of emotional closeness, decreased interactions and intimacy. Moreover they are unable to deal with the feeling of grief^{414, 415}.

5.2.4. Social consequences

⁴⁰⁹ Dang S., Badiye A., Kelkar G. (2008). The dementia caregiver – a primary care ⁴⁰⁹approach. South Medical Journal 101(12): 1246-1251.

⁴¹⁰ Commissaris C.J., Jolles J., Verhey F.R. Jr., Kok G.J. (1995). Problems of caregiving spouses of patients with dementia. Patient Education and Counseling 25(2): 143-149.

⁴¹¹ Brodaty H., Donkin M. (2009). Family caregivers of people with dementia. Dialogues in Clinical Neuroscience 11(2): 217-228.

⁴¹² Dang S., Badiye A., Kelkar G. (2008). The dementia caregiver – a primary care ⁴¹²approach. South Medical Journal 101(12): 1246-1251.

⁴¹³ Brodaty H., Donkin M. (2009). Family caregivers of people with dementia. Dialogues in Clinical Neuroscience 11(2): 217-228.

⁴¹⁴ Zwaanswijk M., Peeters J.M., van Beek A.P., Meerveld J.H.C.M., Francke A.L. (2013). Informal caregivers of people with dementia: problems, needs and support in the initial stage and in subsequent stages of dementia: a questionnaire survey. The Open Nursing Journal 7: 6-13.

⁴¹⁵ Commissaris C.J., Jolles J., Verhey F.R. Jr., Kok G.J. (1995). Problems of caregiving spouses of patients with dementia. Patient Education and Counseling 25(2): 143-149.

Change of the intimacy of the marriage partnership. Dementia patient's apathy and cognitive impairments leads to a lack of intimacy between spouses and enables meaningful conversation and emotional closeness with care recipients^{416, 417} .

Family conflicts. Dementia changes family dynamics and is a serious predictor of conflicts with other family members over the way a caregiving is provided, lack of social and financial support and the decision of placement of dementia patient in nursing facility. It provokes family disharmony and contributes to increased CB^{418, 419, 420, 421, 422} . Caregivers often disagree with other family members about the type of care provided, division of responsibility for caregiving tasks or the need of placement in nursing home⁴²³ .

⁴¹⁶ de Vugt M.E., Riedijk S., Aalten P., Tibben A., Swie ten J., Verhey, F. (2006). Impact of behavioral problems on spousal caregivers: A comparison between Alzheimer's disease and frontotemporal dementia. *Dementia and Geriatric Cognitive Disorders* 22(1): 35-41.

⁴¹⁷ Holley C., Mast B. (2009). The impact of anticipatory grief of caregiver burden in dementia caregivers. *The Gerontologist* 49(3): 388-396.

⁴¹⁸ Connell C.M., Janevic M.R., Gallant M.P. (2001), The costs of caring: impact of dementia on family caregivers. *Journal of Geriatric Psychiatry and Neurology* 14(4): 179-187.

⁴¹⁹ Etters L., Goodall D., Harrison B.E. (2008). Caregiver burden among dementia patient caregivers: a review of the literature. *Journal of American Academy of Nurse Practicioners* 20(8): 423-428.

⁴²⁰ Galvin J.E., Duda J.E., Kaufer D.I., Lippa C.F., Taylor A., Zarit S.H. (2010). Lewy body dementia: caregiver burden and unmet needs. *Alzheimer Disease and Associated Disorders* 24(2): 177-181.

⁴²¹ Nguyen M. (2009). Nurse's assessment of caregiver burden, *Medsurd Nursing* 18(3): 147-151.

⁴²² Schulz R., Beach S.R. (1999). Caregiving as a risk factor for mortality. The caregiver health effects study. *Journal of the American Medical Association* 282(23): 2215-2219.

⁴²³ Zwaanswijk M., Peeters J.M., van Beek A.P., Meerveld J.H.C.M., Francke A.L. (2013). Informal caregivers of people with dementia: problems, needs and support in the initial stage and in subsequent stages of dementia: a questionnaire survey. *The Open Nursing Journal* 7: 6-13.

Caregivers have little time for themselves. Number of hours devoted to DP affects intensity of care and serves as a significant predictor of CB^{424, 425}. As caregivers are on ‘on-call’ for 24 hours a day, seven days a week, and provide an average of 70 hours of care a week⁴²⁶ they have little time for themselves. They are often forced to abandon their leisure activities, give up vacations or hobbies, have little time for other family members and spend less time with their friends^{427, 428, 429, 430, 431, 432}.

Lack of educational programs, and coping resources. Majority of caregivers do not possess adequate knowledge either about dementia, its types, occurrence, symptoms,

⁴²⁴ de Vugt M.E., Riedijk S., Aalten P., Tibben A., Swie ten J., Verhey, F. (2006). Impact of behavioral problems on spousal caregivers: A comparison between Alzheimer's disease and frontotemporal dementia. *Dementia and Geriatric Cognitive Disorders* 22(1): 35-41.

⁴²⁵ Kim H., Chang M., Rose K., Kim S. (2012). Predictors of caregiver burden in caregivers of individuals with dementia. *Journal of Advanced Nursing* 68(4): 846-855.

⁴²⁶ Dang S., Badiye A., Kelkar G. (2008). The dementia caregiver – a primary care ⁴²⁶approach. *South Medical Journal* 101(12): 1246-1251.

⁴²⁷ Brodaty H., Donkin M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience* 11(2): 217-228.

⁴²⁸ Commissaris C.J., Jolles J., Verhey F.R. Jr., Kok G.J. (1995). Problems of caregiving spouses of patients with dementia. *Patient Education and Counseling* 25(2): 143-149.

⁴²⁹ Dang S., Badiye A., Kelkar G. (2008). The dementia caregiver – a primary care ⁴²⁹approach. *South Medical Journal* 101(12): 1246-1251.

⁴³⁰ Galvin J.E., Duda J.E., Kaufer D.I., Lippa C.F., Taylor A., Zarit S.H. (2010). Lewy body dementia: caregiver burden and unmet needs. *Alzheimer Disease and Associated Disorders* 24(2): 177-181.

⁴³¹ Kurz A., Schulz M., Reed P., Wortmann M., Rodrigo J., von Lützu Hohlbein H., Grossberg G. (2008). Personal perspectives of persons with Alzheimer's disease and their carers: a global survey. *Alzheimer's and Dementia* 4(5): 345-352.

⁴³² Schulz R., Martire L.M. (2004). Family caregiving of persons with dementia. Prevalence, health effects, and support strategies. *American Journal of Geriatric Psychiatry* 12(3): 240-249.

treatment or available formal services and coping strategies. Consequently, they are unprepared for providing care^{433, 434}.

Lack of formal support from physicians and the need for professional counseling. During first stages of dementia caregivers often are not sufficiently informed by their physicians about the disease. They do not receive sufficient information about the diagnosis, sometimes receive inadequate diagnosis, have to contact several physicians before they meet proper recognition^{435, 436}. Caregivers want physicians to devote more time on discussing and explaining such issues^{437, 438, 439, 440, 441}. Obtaining medical help is

⁴³³ Galvin J.E., Duda J.E., Kaufer D.I., Lippa C.F., Taylor A., Zarit S.H. (2010). Lewy body dementia: caregiver burden and unmet needs. *Alzheimer Disease and Associated Disorders* 24(2): 177-181.

⁴³⁴ Zwaanswijk M., Peeters J.M., van Beek A.P., Meerveld J.H.C.M., Francke A.L. (2013). Informal caregivers of people with dementia: problems, needs and support in the initial stage and in subsequent stages of dementia: a questionnaire survey. *The Open Nursing Journal* 7: 6-13.

⁴³⁵ Lauriks S., Reinersmann A., van der Roest H.G., Meiland F.J., Davies R.J., Moelaert F., Mulvenna M.D., Nugent C.D., Dröes R.M. (2007) Review of ICT-based services for identified unmet needs in people with dementia. *Ageing Research Reviews* 6(3): 223-246.

⁴³⁶ Prince M., Bryce R., Albanese E., Wimo A., Ribeiro W., Ferri C.P. (2013), The global prevalence of dementia: A systematic review and metaanalysis, *Alzheimer's and Dementia* 9(1): 63-75.

⁴³⁷ Commissaris C.J., Jolles J., Verhey F.R. Jr., Kok G.J. (1995). Problems of caregiving spouses of patients with dementia. *Patient Education and Counseling* 25(2): 143-149.

⁴³⁸ Dang S., Badiye A., Kelkar G. (2008). The dementia caregiver – a primary care ⁴³⁸approach. *South Medical Journal* 101(12): 1246-1251.

⁴³⁹ Gaugler J.E., Kane R.L., Kane R.A., Newcomer R. (2005). Unmet care needs and key outcomes in dementia. *Journal of the American Geriatrics Society* 53(12): 2098-2105.

⁴⁴⁰ Kurz A., Schulz M., Reed P., Wortmann M., Rodrigo J., von Lützu Hohlbein H., Grossberg G. (2008). Personal perspectives of persons with Alzheimer's disease and their carers: a global survey. *Alzheimer's and Dementia* 4(5): 345-352.

⁴⁴¹ Nguyen M. (2009). Nurse's assessment of caregiver burden, *Medsurd Nursing* 18(3): 147-151.

the main unmet need of many caregivers^{442, 443}. They also face problems in communication with health professionals^{444, 445, 446}. Among other problems related to their dissatisfaction with professional help researches point to: indicated the need for additional professional support in caring especially in such domains as: advise concerning methods of dealing with persons with dementia, changes in their behaviors and management of stress, provision of information about progression of dementia, availability of professional support in the region, nursing facilities, emotional and practical support in dealing with the stress, daily life activities and caring for dementia patients^{447, 448, 449}. Caregivers are dissatisfied with the amount and quality of information they receive from physicians. They

⁴⁴² Commissaris C.J., Jolles J., Verhey F.R. Jr., Kok G.J. (1995). Problems of caregiving spouses of patients with dementia. *Patient Education and Counseling* 25(2): 143-149.

⁴⁴³ Dang S., Badiye A., Kelkar G. (2008). The dementia caregiver – a primary care ⁴⁴³approach. *South Medical Journal* 101(12): 1246-1251.

⁴⁴⁴ Commissaris C.J., Jolles J., Verhey F.R. Jr., Kok G.J. (1995). Problems of caregiving spouses of patients with dementia. *Patient Education and Counseling* 25(2): 143-149.

⁴⁴⁵ Leggett A., Zarit S., Taylor A., Galvin J. (2010). Stress and burden among caregivers of patients with Lewy body dementia. *The Gerontologist* 51(1): 76-85.

⁴⁴⁶ Li H. (2012). Unmet service needs: a comparison between dementia and non-dementia caregivers. *Home Health Care Services Quarterly* 31(1): 41-59.

⁴⁴⁷ Lauriks S., Reinersmann A., van der Roest H.G., Meiland F.J., Davies R.J., Moelaert F., Mulvenna M.D., Nugent C.D., Dröes R.M. (2007) Review of ICT-based services for identified unmet needs in people with dementia. *Ageing Research Reviews* 6(3): 223-246.

⁴⁴⁸ Li H. (2012). Unmet service needs: a comparison between dementia and non-dementia caregivers. *Home Health Care Services Quarterly* 31(1): 41-59.

⁴⁴⁹ Zwaanswijk M., Peeters J.M., van Beek A.P., Meerveld J.H.C.M., Francke A.L. (2013). Informal caregivers of people with dementia: problems, needs and support in the initial stage and in subsequent stages of dementia: a questionnaire survey. *The Open Nursing Journal* 7: 6-13.

also believe that professionals fail to provide them with adequate emotional and psychological help and support^{450, 451, 452, 453}.

The need to rely on external social supports outside the family including institutionalization. CB is a strong predictor of earlier nursing home placement (NHP)^{454, 455}. And while NHP may help in reducing CB it may also increase it⁴⁵⁶. Development of dependence and patient's disturbing behaviors are the primary reason for institutionalization (Thomas et al 2004) just as lack of professional and informal support⁴⁵⁷.

⁴⁵⁰ Commissaris C.J., Jolles J., Verhey F.R. Jr., Kok G.J. (1995). Problems of caregiving spouses of patients with dementia. *Patient Education and Counseling* 25(2): 143-149.

⁴⁵¹ Dang S., Badiye A., Kelkar G. (2008). The dementia caregiver – a primary care⁴⁵¹ approach. *South Medical Journal* 101(12): 1246-1251.

⁴⁵² Kurz A., Schulz M., Reed P., Wortmann M., Rodrigo J., von Lützu Hohlbein H., Grossberg G. (2008). Personal perspectives of persons with Alzheimer's disease and their carers: a global survey. *Alzheimer's and Dementia* 4(5): 345-352.

⁴⁵³ Lauriks S., Reinersmann A., van der Roest H.G., Meiland F.J., Davies R.J., Moelaert F., Mulvenna M.D., Nugent C.D., Dröes R.M. (2007) Review of ICT-based services for identified unmet needs in people with dementia. *Ageing Research Reviews* 6(3): 223-246.

⁴⁵⁴ Etters L., Goodall D., Harrison B.E. (2008). Caregiver burden among dementia patient caregivers: a review of the literature. *Journal of American Academy of Nurse Practicioners* 20(8): 423-428.

⁴⁵⁵ Spillman B., Long S. (2009). Does high caregiver stress predict nursing home entry. *Inquiry* 46(2):140-161.

⁴⁵⁶ Brodaty H., Donkin M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience* 11(2): 217-228.

⁴⁵⁷ Commissaris C.J., Jolles J., Verhey F.R. Jr., Kok G.J. (1995). Problems of caregiving spouses of patients with dementia. *Patient Education and Counseling* 25(2): 143-149.

5.3. Unmet needs of caregivers

According to the literature⁴⁵⁸, ⁴⁵⁹ the most common unmet needs of informal caregivers are related to lack of professional support in care, and include:

1. the need for information about diagnosis, stages of dementia and the course of the disease, about possible problems for the patient and the caregiver, ways of managing difficult behaviors, coping strategies, goals of care and organizations that provide help;
2. the need for advice how to manage dementia patient's feelings of being afraid, angry or confused, how to deal with his or her apathy, how to cope with change in patient's behavior, what activities to undertake with the patient and how to deal with aggression of dementia patient;
3. the need for (printed) information, including the availability of professional support services in the region, including interdisciplinary teams, legal advice in case of placing a patient in the nursing house, information about the disease and its progression;
4. due to the problems of loneliness and loose of contact with relatives and friends they express the need for emotional support, especially when a caregiver experiences feeling of being abandoned and in times
5. as caregiving becomes physically to demanding they express the need for practical support: day care and assistance with housekeeping in and around the house.
6. the need for financial support with home as the lack resources necessary to make environmental changes in the home, such as assistive devices in the bathroom, special locks on outside doors and professional equipment for the therapy.

In sum, caregivers unmet needs include:

1. the need for general and personalized information,
2. the need for support with regard to symptoms of dementia,
3. the need for social contact and company,

⁴⁵⁸ ibidem

⁴⁵⁹ Dang S., Badiye A., Kelkar G. (2008). The dementia caregiver – a primary care ⁴⁵⁹approach. South Medical Journal 101(12): 1246-1251.

4. the need for health monitoring and perceived safety,
5. the need to make necessary environmental arrangements,
6. the need for social and medical service, including emergency services, psychiatric care, rehabilitation service and law enforcement,
7. the need for web-based information, directories of dementia expert providers, information on dementia research,
8. the need for local support groups.

According to some researches caregiver's well-being and caregiving burden is not so much determined by the duration and severity of the disease as by the availability of the resources and support ^{460, 461} including information about the disease, advice of management of its symptoms and social and financial support. Consequently, it is important to realise that caring for caregivers not only results in reducing their CB, but also helps the dementia patient and benefits community and the State.

7.1 Caregiving burden in Poland

Like in many other parts of the world the number of the elderly population in Poland is increasing. Central Statistical Office (Główny Urząd Statystyczny) estimates that by the year 2035 the percentage of people above 65 years of age will double to reach

⁴⁶⁰ Brodaty H., Green A., Koschera A. (2003). Meta-analysis of psychosocial interventions for caregivers of people with dementia. *Journal of the American Geriatrics Society* 51(5): 657-664.

⁴⁶¹ Commissaris C.J., Jolles J., Verhey F.R. Jr., Kok G.J. (1995). Problems of caregiving spouses of patients with dementia. *Patient Education and Counseling* 25(2): 143-149.

23.8% of Polish population^{462, 463}. It is important as the prevalence of dementia among the elderly doubles every five years from 1% among those aged 60-65 to over 40% among those aged 85. The current number of dementia patients in Poland is estimated at the level of 400 thousands out of which 50-70% suffer from Alzheimer disease⁴⁶⁴. What is important is that 92% of dementia patients in Poland are cared for in homes by their family members from the early onset of the disease until their death⁴⁶⁵. Another problem is that most of Polish informal caregivers are spouses, who are also aged over sixty and for that reason often suffer from disability. Nevertheless, Poland lacks any official registry of informal caregivers. Moreover it like in many other countries the availability of care services for both people with dementia and their caregivers is inadequate. According to Kaczmarek et al (2010) in Poland only 3% of dementia patient reside in residential institutions and only 6% of caregivers feel satisfied with organization of care for dementia patient⁴⁶⁶.

The most important factors affecting CB among Polish informal caregivers include:

1. job restrictions and problems with employment: missing work, being tired at work, missing new job opportunities or chances of promotion;
2. lack of formal support from government and social institutions;

⁴⁶² Kaczmarek M., Durda M., Skrzypczak M., Szwed A. (2010). Ocena jakości życia opiekunów osób z chorobą Alzheimera. *Gerontologia Polska* 18(2): 86-94.

⁴⁶³ Karczewska B., Bień B., Ołdak E., Jamiółkowski J. (2012). Opiekunowie rodzinni osób starszych z otępieniem lub zaburzeniami poznawczymi w Polsce — czynniki ryzyka obciążenia opieką. *Gerontologia Polska* 20(2): 59-67.

⁴⁶⁴ Kaczmarek M., Durda M., Skrzypczak M., Szwed A. (2010). Ocena jakości życia opiekunów osób z chorobą Alzheimera. *Gerontologia Polska* 18(2): 86-94.

⁴⁶⁵ Durda M. (2010) Organizacja opieki nad osobami z demencją w Polsce na tle krajów rozwiniętych i rozwijających się. *Gerontologia Polska* 18(2): 76-85.

⁴⁶⁶ Kaczmarek M., Durda M., Skrzypczak M., Szwed A. (2010). Ocena jakości życia opiekunów osób z chorobą Alzheimera. *Gerontologia Polska* 18(2): 86-94.

3. insufficient medical information on dementia and professional counseling regarding caregiving and treatment;
4. patients' disturbing behaviors and personality changes, especially impulsiveness and aggression, emotional liability, lack of cooperation with caregiver, night wandering, delusions, immobility, incontinence, decreased ADL and IADL;
5. negative influence of dementia on relations with other family members;
6. lack of financial support or insurance (caregivers can afford only up to 14 days of leave during the year);
7. lack of professional equipment ^{467, 468}.

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⁴⁶⁷ ibidem

⁴⁶⁸ Durda M. (2010) Organizacja opieki nad osobami z demencją w Polsce na tle krajów rozwiniętych i rozwijających się. *Gerontologia Polska* 18(2): 76-85.

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5. Tools used in diagnosis

There are no legal barriers in the State Regulation Concerning Basic Health Services issues by the Minister of Health which would prevent GPs from diagnosing dementia. There is no list of diseases either which should be diagnosed by specialists only.⁴⁷⁰

In Poland, some GPs who suspect dementia treat patients themselves while others refer patients to specialists. The specialists who can diagnose dementia and/or Alzheimer's disease are neurologists, psychiatrists and geriatricians.

GPs use screening tests like the MMSE and the clock drawing test to assess dementia provided that they possess the relevant knowledge and that such tests are available. Often, GPs diagnose dementia just on the basis of the consultation with the patient and/or family. Often, they do not attempt to diagnose a particular disease, like Alzheimer's disease, and undertake treatment simply because they have no right to order an examination like a CT or psychological examination. Only a specialist can decide on that. Also, there is a fear that in the absence of a consultation with a specialist, the patient will not be entitled to purchase the drugs at a lower price with reimbursement from the state. If a GP prescribes drugs without a consultation with a specialist, the patient has to pay 100% as otherwise the GP would have to refund the cost of the treatment. Consequently, in practice, GPs either diagnose dementia and do not refer the patient to specialists or diagnose dementia but send the patient to a specialist for a more detailed, accurate diagnosis⁴⁷¹.

There is no set consultation time in any regulations or agreements with medical staff. The duration of the consultation may differ according to the size of the clinic and the number of patients registered in it. Patients usually have an appointment for 15 minutes but on average they have ten-minute consultations. They depend on how many patients have appointments on a particular day, the season (i.e. there are more patients with colds in winter) and whether the doctor devotes any of his/her free time. Patients with pain,

⁴⁷⁰ Dementia in Europe Yearbook 2012

⁴⁷¹ *ibidem*

fever or something urgent do not need to have an appointment and have to be treated as if it were an emergency.

The consultation time can be extended but there is no regulation on this, so it just depends on the GP and the number of patients s/he has to consult on a particular day.

The National Health Service pays GPs who work out-patient clinics, taking into account the total number of patients registered in a particular clinic but not how much work each GP does, how many patients s/he consults each day or how many diagnostic tests s/he carries out. The higher the number of older patients registered in a particular out-patient clinic, the more money the clinic receives, This is insufficient to serve as an incentive to GPs to devote more time to patients with dementia and thereby improve or increase timely diagnosis⁴⁷².

There are some guidelines issued by the Family Doctors' Collegium as well as by researchers' associations. There are no official guidelines from the National Health Service or Ministry of Health on diagnosing dementia. The Polish Alzheimer's Association has published and distributed a leaflet addressed to GPs with prepared by leading specialists in the diagnosis and treatment of dementia outlining steps which should be taken when a GP suspect dementia. However, as in other specializations, there is no requirement for GPs to follow any guidelines to diagnose dementia and/or Alzheimer's disease as recommendations in Poland are not obligatory for doctors. As diagnostic guidelines and tests are not available at every out-patient clinic, GPs usually refer patients with memory problems to specialists.⁴⁷³ Dementia has been made for full accessibility of drugs used in AD treatment. The drugs should be available free of charge or with 70% reimbursement.

The availability of medicines in general

Medicines in Poland can fall under one of three different reimbursement systems:

- For basic medicines, patients pay a fixed price of PLN 3.25 (approx. Eur 0.82) to PLN 5.00 (approx.. EUR 1.27) as determined by the Minister of Health,

⁴⁷² Dementia in Europe Yearbook 2012.

⁴⁷³ ibidem

- For special additional medicines, patients pay 30% to 50% of the cost,
- For all other medicines, patients pay the totality of the cost.

Hospital medicines are free of charge.⁴⁷⁴

a. Tools for assesment of dementia patients

Quality of life

Quality of Life–Alzheimer’s Disease Scale (QOL-AD)

Consists of 13 items, rated in a 13-point scale (from 1 – poor to 4 – excellent) used to asses dementia patient’s quality of life.

- Logsdon R.G., Gibbons L.E., McCurry S.M., Teri L. (1998). *Quality of life in Alzheimer's disease: Patient and caregiver report*. Journal of Mental Health and Aging 5(1): 21-32.
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COGNITIVE FUNCTIONS:

Mini Mental State Examination (MMSE)

Is a 30-point questionnaire used to screen cognitive impairment in dementia patients. It helps to evaluate the progress of cognitive impairment over time. It includes arithmetic, memory and orientation items.

- Folstein M.F., Folstein S.E., McHugh P.R. (1975). *Mini-mental state. A practical method for grading the cognitive state of patients for the clinician*. Journal of Psychiatric Research 12(3): 189-198.

Neuropsychiatric Inventory (NI)

It assess frequency and the severity of 10 behavioral disturbances occurring in dementia patients: delusions, hallucinations, dysphoria, anxiety, agitation/aggression, euphoria,

⁴⁷⁴ Ibidem.

disinhibition, irritability/lability, apathy, and aberrant motor activity. Information for the NPI is obtained from a caregiver familiar with the patient's behavior.

- Cummings J.L., Mega M., Gray K., Rosenberg-Thompson S., Carusi D.A., Gornbein J. (1994) *The Neuropsychiatric Inventory: comprehensive assessment of psychopathology in dementia*. *Neurology* 44(12): 2308-2314.
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Boston Naming Test (BNT)

Contains 60 drawings graded in difficulty from “bed” (easy, high frequency) to “abacus” (difficult, low frequency). Patients are told to name each picture in about 20 seconds for each picture.

- Kapla E., Goodglass H., Weintraub S. (1983). *Boston Naming Test*. Philadelphia: Lea & Febiger.

Verbal Fluency Tests (VFT)

It involves the patient naming as many animals as possible within a 60-second time period. If the patient named 15 or fewer animals within that time this may indicate early stages of dementia or the development of a cognitive impairment.

- Sebaldt R., Dalziel W., Massoud F., Tanguay A., Ward R., Thabane L., Melnyk P., Landry P.A., Lescrauwaet B. (2009) *Detection of cognitive impairment and dementia using the animal fluency test: the DECIDE study*. *The Journal of the Neurological Sciences* 36(5): 599-604.

Clock Drawing Test (CDT)

It is used for screening for cognitive impairment and dementia and as a measure of spatial dysfunction and neglect. The patient is instructed to draw the numbers within a pre-drawn circle 33/x inches in diameter to make that circle look like the face of a clock.

- Watson I.Y., Arfken C.L., Birge S.J. (1993). *Clock Completion: An Objective Screening Test for Dementia*. *Journal of the American Geriatrics Society* 41(11): 1235-1240.

- Agrell B., Dehljn O., (1998). *The clock-drawing test*. Age and Ageing 27: 399-403.

Wechsler Memory Scale (WMS)

It is used to evaluate clinically relevant aspects of memory functioning, including logical memory, verbal paired associates and visual reproduction, spatial addition and design memory.

- Brooks D.N. (1976). *Wechsler Memory Scale performance and its relationship to brain damage after severe closed head injury*. Journal of Neurology, Neurosurgery, and Psychiatry 39(6): 593-601.

Controlled Oral Word Association Test (COWAT)

Is designed to measure person's ability to make verbal associations to specified letters. It is able to detect changes in word association fluency often found with various disorders

- Sumerall S.W., Timmons P.L., James A.L., Ewing M.J., Oehlert M.E. (1997). *Expanded norms for the Controlled Oral Word Association Test*. Journal of Clinical Psychology 53(5): 517-521.

Trail Making Test (TMT)

It consists of two parts in which the patient is asked to connect a set of 25 numbered dots as fast as possible. It helps to assess visual search speed, scanning, speed of processing, mental flexibility and executive functioning.

- Tombaugh, T.N. (2004). *Trail Making test A and B: normative data stratified by age and education*. Archives of Clinical Neuropsychology 19(2): 203-214.

Rey-Osterrieth Complex Figure Test (ROCF)

Is designed to evaluate different functions, such as visuospatial abilities, memory, attention, planning, and working memory. Patient is asked to reproduce a complicated line drawing, first by copying and then from memory.

- Duley J.F., Wilkins J., Hamby S., Hopkins D., Burwell R., Barry N. (1993). *Explicit scoring criteria for the Rey-Osterrieth and Taylor complex figures*. The Clinical Neuropsychologist 7(1): 29-38.

Ruff Figural Fluency Test (RFFT)

Consists of five 60-second parts, each with a different stimulus presentation. The respondent draws as many unique designs as possible within 60 seconds by connecting the dots in different patterns. The total number of unique designs drawn constitutes the main score. It helps to evaluate nonverbal capacity for fluid and divergent thinking, ability to shift cognitive set, planning strategies, and executive ability to coordinate this process.

- Ruffa R.M., Lightb R.H., Evansc R.W. (1987). *The ruff figural fluency test: A normative study with adults*. Developmental Neuropsychology 3(1): 37-51.
- Foster P.S., Williamson J.B., Harrison D.W. (2005). *The Ruff Figural Fluency Test: heightened right frontal lobe delta activity as a function of performance*. Archives of Clinical Neuropsychology 20(4): 427-434.

Wisconsin Card Sorting Test (WCST)

It involves matching cards according to different principles and to alter their approach during test administration. It measures such executive function as strategic planning, organized searching, utilizing environmental feedback to shift cognitive sets, directing behavior toward achieving a goal, and modulating impulsive responding.

- Greve K.W., Stickel T.R., Love J., Bianchini K.J., Stanford M.S. (2005) *Latent structure of the Wisconsin Card Sorting Test: a confirmatory factor analytic study*. Archives of Clinical Neuropsychology 20(3): 355-364.

ADL and IADL

Disability Assessment for Dementia (DAD)

Is a 40 items tool for assessment of functional disability of dementia patients. It consists of 17 related to basic self-care items and another 23 which measure instrumental activities of daily living.

- Gelinas I., Gauthier L., McIntyre M. (1999). *Development of a functional measure for persons with Alzheimer's disease: the Disability Assessment for Dementia*. American Journal of Occupational Therapy 53(5): 471-481.
- Feldman H., Sauter A., Donald A., Gélinas I., Gauthier S., Torfs K., Parys W., Mehnert A. (2001). *The disability assessment for dementia scale: a 12-month study of functional ability in mild to moderate severity Alzheimer disease*. Alzheimer Disease and Associated Disorders 15(2):89-95.

Activities of Daily Living scale (ADLS)

- Katz S., Ford A.B., Moskowitz R.W. (1963). *Studies of illness in the aged. The Index of ADL: a standardized measure of biological and psychosocial function.* Journal of the American Medical Association 185(12): 914-919.

Physical Self-Maintenance Scale (PSMS)

Is a 6 item scale designed to measures basic activities such as bathing eating and using the toilet. Each is rated on a 5-point scale

- Lawton M.P., Brody E.M. (1969) *Assessment of older people: self-maintaining and instrumental activities of daily living.* The Gerontologist 9(3):179-186

Instrumental Activities of Daily Living Scale (IADLS)

- Powell Lawton M., Brody E.M. (1969). *Assessment of older people: self-maintaining and Instrumental Activities of Daily Living.* The Gerontologist 9(3):179-186.

Cornell Scale for Depression in Dementia (CSDD)

Each item is rated for severity on a scale of 0 (absent) to 2 (severe). Scores above 10 indicate a probable major depression, and above 18 a definitive major depression. Scores below 6 are associated with absence of significant depressive symptoms.

- Barca M.L., Selb k G., Laks J., Engedal K. (2008). *The pattern of depressive symptoms and factor analysis of the Cornell Scale among patients in Norwegian nursing homes.* International Journal of Geriatric Psychiatry. 23(10): 1058-1065
- Alexopoulos G.S., Abrams R.C., Young R.C., Shamoian C.A. (1988). *Cornell Scale for Depression in Dementia.* Biological Psychiatry 23(3): 271-284.

CES-D Scale

Radloff Lenore Sawyer (1977) *The CES-D Scale: A Self-Report Depression Scale for Research in the General Population,* Applied Psychological Measurement 1(3):385-401.

This scale is also available in a revised version as CESD-R (<http://cesd-r.com/>)

1. Bobak M., Pikhart H., Pajak A., Kubinova R., Malyutina S., Sebakova H., Topor-Madry R., Nikitin Y., Marmot M. (2006) *Depressive symptoms in urban population samples in Russia, Poland and the Czech Republic*. British Journal of Psychiatry 188: 359-365.
2. Cho M.J., Kim K.H. (1998) *Use of the Center for Epidemiologic Studies Depression (CES-D) Scale in Korea*. Journal of Nervous and Mental Disease 186(5):304-310.
3. Eaton W.W., Kessler L.G. (1981) *Rates of symptoms of depression in a national sample*. American Journal of Epidemiology 114:528-538.
4. Murphy J.M. (2002) *Symptom scales and diagnostic schedules in adult psychiatry*. In: Tsuang M.T., Tohen M. (eds.) *Textbook in Psychiatric Epidemiology*. New York: Wiley-Liss: 273-332.
5. Myers J.K., Weissman M.M. (1980) *Use of a self-report symptom scale to detect depression in a community sample*. American Journal of Psychiatry 137(9):1081-1084.
6. Naughton M.J., Wiklund I. (1993) *A critical review of dimension-specific measures of health-related quality of life in cross-cultural research*. Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care & Rehabilitation 2(6): 397-432.
7. Roberts R.E. (1980) *Reliability of the CES-D scale in different ethnic contexts*. Psychiatry Research 2(2):125-134.

This scale is amongst a number used in Poland. Here are a few works that have applied it as a tool of measurement:

1. Bobrowski K. (2006) *Zdrowie psychiczne i zachowania ryzykowne 15-latków – badania mokotowskie* [Mental health and risk behaviours among 15-year-olds - Mokotów study]. Alkoholizm i Narkomania 19(3): 225-242.
2. Czabała J.C., Brykczyńska C., Ostaszewski K., Bobrowski K. (2005) *Problemy zdrowia psychicznego w populacji gimnazjalistów warszawskich* [Mental health problems in the high school student population in Warsaw]. Postępy Psychiatrii i Neurologii 14(1): 1-9
3. Dojka E., Górkiewicz M., Pajak A. (2003) *Wartość pomiarowa skali CES-D do oceny depresji w populacji polskiej* [Measured value of the CES-D scale for the assessment of depression in the Polish population]. Psychiatria Polska 37(2): 281-292.

4. Pilarska, A. (2010) *Cechy samoświadomości a nasilenie symptomów depresji* [Characteristics of self-awareness and the severity of depressive symptoms]. *Roczniki Psychologiczne* 13(2): 181-197.

Other recommended scales

1. Montgomery Asberg Depression Rating Scale
2. the Quick Inventory of Depressive Symptoms – Self Report 16 Item (QIDS-SR16)
3. Zung Self-Rating Depression Scale

6. Grey knowledge about dementia care

6.1. The image of online support groups for caregivers of patients with Alzheimer's disease

The twentieth century brought a very dynamic development of the idea of self-help and the numerous movements dealing with this issue, including different support systems for people with similar problems, such as health problems. Those ideas arose from imperfect health systems, the unfulfilled needs of patients and lack of social support in traditionally practiced medicine⁴⁷⁵.

There are many movements and forms of self-help among those caring for people with Alzheimer's disease. There are support groups in hospital wards, nursing homes, hospices and social welfare institutions. One can find several websites for carers of people with dementia on the Internet. They often contain fragmentary knowledge and tips on the disease of little use, and therefore it can be observed that carers come together on Internet forums. Caregivers frequently ask questions and raise issues related to a specific symptom of the patient in the online setting. It is often possible to find the full history and progress of the disease, which can be the source of gaining knowledge and sharing information about the disease. Caregivers receive either no or insufficient real world help in the form

⁴⁷⁵ Turuk-Nowak T. Pomoc psychologiczna pacjentom onkologicznym. Zmagając się z chorobą nowotworową [Psychological support for cancer patients. Struggling with cancer]. In: Kubacka-Jasiecka D., Łosiak D. (ed.). Wydawnictwo Uniwersytetu Jagiellońskiego, Kraków 1999; 237-41.

of information provision, rehabilitation provision, working with families, professionals and institutions, and sometimes financial assistance.

Online forums also contain many topics related to mental and physical exhaustion of the caregivers. Caring for a family member with dementia is very hard and carers have to show great patience and understanding. They are often lonely, forced to care day and night for the sufferer, which results in social isolation. The behaviour of the patient is very unpredictable so the caregiver constantly struggles with new situations. In order to deal with it they need professional support and extensive knowledge. “As Jolanta explains: patients are lost in their environment, they behave abnormally, even strangely, e.g. they hide various objects in the strangest places and then they look for them [...] Patients persistently repeat something, are physically hyperactive, aggressive or even refuse to perform basic tasks such as washing up [...] These behaviours cause surprise or seem to be funny, or raise suspicion of malice, cause discouragement and frustration, says Ms Węsierska [...] Alzheimer's disease is often mistakenly associated with a mental illness, but it is in fact a neurological disorder [...] What is needed is medication, therapy and a lot of patience”⁴⁷⁶.

Such intense and burdensome care must have a destructive impact on the familial, professional and social lives of carers, which leads to such consequences of chronic stress as insomnia, irritability, anger, shame, loss of self-esteem, guilt, depression, and aggressive behaviour (active and passive) towards the patient. It also contributes to higher prevalence of serious health problems among caregivers - mainly heart diseases, high blood pressure, osteoarthritis, diabetes and gastric disorders. “It has been proven that caring for patients with dementia is more tedious and stressful than for people with physical illnesses”⁴⁷⁷. This is even greater in the case of financial problems, lack of

⁴⁷⁶ Kuczmarska A. Opiekują się swoimi bliskimi i wspierają siebie nawzajem [They take care of their loved ones and support each other]. *Puls Wejherowa*. <http://pulswejherowa.pl/start/531-opiekuj-si-swoimi-bliskimi-i-wspieraj-siebie-nawzajem> , 10.03.2013

⁴⁷⁷ Polskie Towarzystwo Psychiatryczne. Sekcja Psychogeriatrrii i Choroby Alzheimer'a. Standardy postępowania [Polish Psychiatric Association. Geriatric psychiatry and Alzheimer's disease Section. Standards of conduct]. http://www.alzh.pl/standardy_2_14.html , 10.03.2013

adequate knowledge about the disease and the principles of care, or the inability to cope with new or mounting medical problems of patients.

Caregivers often face a lack of understanding on the part of other members of their family and society, which might lead them providing care in isolation. Online forums highlight many of the problems faced by caregivers of people with Alzheimer's disease and show how important it is for them to have mutual emotional support, which is often missing in the 'real world'.

“That is why psychological and material support of the carers, providing them with the help of other people and regular rest, are integral parts of caring for a patient with dementia [...] Support group meetings, which should be attended by both caregivers and patients, provide emotional release connected with care and the exchange of experiences, and provide practical tips on the course of the disease [...] The carer also has the possibility of getting legal advice, information on caring products and rehabilitation equipment”⁴⁷⁸.

b. Problems of caregivers. Posts from Internet forums. How do you recognize the onset of the disease and help the patient?

Problems arise from the very beginning. Firstly, people see a change in the behaviour of a loved one, but they cannot diagnose it properly. They do not know if this is the right moment when they should consult a specialist. The problem mainly concerns the assessment of the elderly. Many assume that certain problems are a normal part of old age and they cannot accurately distinguish whether memory problems are due to aging or a disease. A person nicknamed Matsu says on an Internet forum:

“After grandpa's death, grandma got her first stroke, but she recovered from it with some minor damage and that is why we did not notice (neither us, nor grandma) any changes. We trivially missed the onset of the disease”⁴⁷⁹.

⁴⁷⁸ Ibidem.

⁴⁷⁹ Forum dyskusyjne Małopolskiej Fundacji Pomocy Ludziom Dotkniętym Chorobą Alzheimera [Discussion Forum, Malopolska Foundation for Those Affected by Alzheimer's Disease] <http://forum.alzheimer-krakow.pl/viewforum.php?f=4&sid=3e3b310f1293f128f82cb9ac6cbb8358>, 10.03.2013

Another problem arises when the caregiver realises that the disease is probably starting and they want them to consult their doctor. Patients often see suggestions to visit the hospital as suspicious and there are situations when they strongly refuse to go for a consultation. During an appointment they claim that everything is all right. A person wrote:

“My father does not want to hear about the visit to the doctor. (...) after the interview the neurologist wanted my father to have a three day observation and a tomography of the brain with contrast, but my father discharged himself from hospital of his own volition and the neurologist could not clearly determine the disease. Anyway, when my father is at a doctor's, etc. he instantly becomes lively and lies that everything is ok, and that he only has a pain in his knee ”⁴⁸⁰.

How to provide care? Many carers of people with dementia or Alzheimer's disease ask questions on forums related to caring for the sick. They touch upon most issues and problems related to a particular behaviour. Hospitals often have their own special ways of dealing with such situations, no one, however, gives tips to carers on how to deal with patients in domestic conditions. In addition to issues like problems with feeding a person who does not want to eat and destroying diapers, there are also others such as:

Control over the patient's finances:

“we are concerned about her giving away money or that someone will cheat grandmother financially as we have noticed her problems with using cash. Would it be a good solution to pay them to an account so that it was safe?” – Natalia⁴⁸¹.

⁴⁸⁰ Forum Neurologiczne. Portal Wiedzy O Neurologii [Neurological Forum, Portal of Neurology]. <http://www.forumneurologiczne.pl/forum/vt,0,407,24692,160,demencja-starczaalzheimer-bezradnosc-rodziny>, 10.03.2013

⁴⁸¹ Forum dyskusyjne Małopolskiej Fundacji Pomocy Ludziom Dotkniętym Chorobą Alzheimera [Discussion Forum, Małopolska Foundation for Those Affected by Alzheimer's Disease] <http://forum.alzheimer-krakow.pl/viewforum.php?f=4&sid=3e3b310f1293f128f82cb9ac6cbb8358>, 10.03.2013

The administration of medicines:

“I have taken away the medicines from my mum. She does not steal them, as they are hidden so well that she will not find them. (...) Now she argues about them with me.” –Iwona⁴⁸².

General behaviour:

“I'm looking for any tips on how to behave in order to silence her. Can our behaviour have any real impact on her?” – mala ⁴⁸³.

Where to look for support, advice and information? There are often forum posts reporting no professional help. A woman writes:

“we go to the doctor with my mother in law but we lack the support to know how to deal with such a person, even at home, so that there was no threat to life” ”-

justyna_marchewa1⁴⁸⁴;

“I would like to receive support from you because I really struggle with this disease on my own (...).I'm counting on your help and support in the form of a conversation.”-Dora87⁴⁸⁵;

Lack of reliable information about the disease and support options:

“Maybe my expectations are too high, but still, no doctor has been able to tell me more about the disease than I already know”-e-de ⁴⁸⁶; “At this point, I thought of the day stay

⁴⁸² Alzheimer – Forum Opiekunów [Alzheimer's – Carers' Forum]. <http://www.alzheimer-opiekuni.pl/forum/index.php> , 10.03.2013

⁴⁸³ Ibidem.

⁴⁸⁴ Forum Psychologiczne. Nerwica Depresja Psychologia [Psychological Forum. Anxiety Depression Psychology]. <http://www.nerwica.com/alzheimer-t7305.html> , 10.03.2013

⁴⁸⁵ Forum dyskusyjne Małopolskiej Fundacji Pomocy Ludziom Dotkniętym Chorobą Alzheimera [Discussion Forum, Małopolska Foundation for Those Affected by Alzheimer's Disease] <http://forum.alzheimer-krakow.pl/viewforum.php?f=4&sid=3e3b310f1293f128f82cb9ac6cbb8358> , 10.03.2013

⁴⁸⁶ Ibidem.

and treatment for people with Alzheimer's disease, an eight hour one when I am at work. However, I have no idea if there is anything like this in Wroclaw”- Dora87⁴⁸⁷.

Forum users report that these problems affect both themselves and their patients. The statement may indicate how important it is for them to have all the information and sense of community:

“It's nice that you can listen to my woes and give valuable advice!”-Dora87⁴⁸⁸

Demanding and long-term care of the sick is very time-consuming and exhausting for carers. It causes multiple emotional and psychological problems, e.g. stress:

“I constantly live in stress. Anxiety. Continuous remorse. I cease to deal with it. It breaks my heart... I suspect that the stress contributed to the fact that I miscarried the last two pregnancies”- e-de⁴⁸⁹;

The inability to come to terms with the new situation:

“I have a lot in common with him and I admit that I am horribly affected by it but I can see that I am only in his memories”- ewaewa⁴⁹⁰;

Lack of perspective:

“I see mum deals with it badly. Any behaviour of my father knocks her off balance, and she is unable to keep perspective”-Marcepan⁴⁹¹;

Helplessness:

“Grandma does not listen to anyone, even grandfather has lost his influence on her. We feel very helpless”- Minia⁴⁹²

⁴⁸⁷ Ibidem.

⁴⁸⁸ Ibidem.

⁴⁸⁹ Ibidem.

⁴⁹⁰ Ibidem.

⁴⁹¹ Ibidem.

⁴⁹² Forum dyskusyjne Małopolskiej Fundacji Pomocy Ludziom Dotkniętym Chorobą Alzheimera [Discussion Forum, Małopolska Foundation for Those Affected by Alzheimer's Disease]. <http://forum.alzheimer-krakow.pl/viewforum.php?f=4&sid=3e3b310f1293f128f82cb9ac6cbb8358> , 10.03.2013.

Physical health:

“We are exhausted mentally, but our physical health starts being affected as well. Grandpa has to be dragged and led to the toilet (...)” – Wiosna⁴⁹³;

Caregivers often struggle with many fears and moral dilemmas. A large number of posts on the forum contain concerns about or even open aversion to nursing homes. Apart from the lack of money, people are afraid to put their loved ones into such homes for fear of bad care. Many also have an inner feeling that they throw out their loved ones when they are problematic, and they do not realise that the care in such centres is often much less stressful and much safer than the care at home:

“I cannot imagine my life without grandpa but how much longer will we be able to withstand it?”-Wiosna[9]; “I do not want to put him anywhere, but on the other hand (...)”-ewaewa⁴⁹⁴;

Fear of incorrect diagnosis:

“I am horrified that doctors give such a diagnosis so easily, because it makes their treatment difficult”-Annpar⁴⁹⁵

Resignation from work is a consequence resulting from caring for the sick. A large number of people who write on forums tell about leaving their jobs to care for an elderly person. It often results from indifference of the rest of the family when the responsibility for the sufferer falls to one person. Caregivers, therefore, fully engage themselves with supporting the patient because of a sense of duty:

“It has got so much worse recently that I had to give up my job.” – Acuarela⁴⁹⁶;

⁴⁹³ Forum dyskusyjne Małopolskiej Fundacji Pomocy Ludziom Dotkniętym Chorobą Alzheimerą
[Discussion Forum, Malopolska Foundation for Those Affected by Alzheimer's Disease]
<http://forum.alzheimer-krakow.pl/viewforum.php?f=4&sid=3e3b310f1293f128f82cb9ac6cbb8358> ,
10.03.2013

⁴⁹⁴ Ibidem.

⁴⁹⁵ Ibidem.

⁴⁹⁶ Ibidem.

Loosing one's circle of friends is often a consequence of spending whole days with the patient, which makes carers lonely and depressed:

“Like in many families the care falls to one person. No contact with people sometimes drives me insane”; “I had to forget about my friends, I have only a handful now. My partner will not stand it, but I'm not surprised” -Matsu⁴⁹⁷;

The loss of social skills by people who deal with the sick for many years.

They change the way they function so much that they can no longer function normally:

“It scares me that I cannot function normally and now it is a real prison, because I don't even leave home (...)I have no patience for healthy, living people. I avoid them like the plague ” – Joanna⁴⁹⁸;

Reaction of society, which is often very negative is also very problematic to the carer. People often do not know enough about the disease, which results in an inadequate assessment of Alzheimer's and other forms of dementia as well as the display of resentment towards the family:

“She has a strange attitude towards father, and his inability to work is seen as laziness. She argues with him, insults him, and she is not able to understand his disease. ” –Marcepan⁴⁹⁹;

⁴⁹⁷ Forum dyskusyjne Małopolskiej Fundacji Pomocy Ludziom Dotkniętym Chorobą Alzheimera [Discussion Forum, Malopolska Foundation for Those Affected by Alzheimer's Disease]. <http://forum.alzheimer-krakow.pl/viewforum.php?f=4&sid=3e3b310f1293f128f82cb9ac6cbb8358> , 10.03.2013.

⁴⁹⁸ Forum Psychologiczne. Nerwica Depresja Psychologia [Psychological Forum. Anxiety Depression Psychology]. <http://www.nerwica.com/alzheimer-t7305.html> , 10.03.2013

⁴⁹⁹ Alzheimer – Forum Opiekunów [Alzheimer – Carers' Forum]. <http://www.alzheimer-opiekuni.pl/forum/index.php> , 10.03.2013.

Some people also underestimate the burden that fell to the carers. They accuse them of negligence, or blame the family for abusing the sick, which is expressed in a women's post on the forum:

“on average twice a week our neighbours (suddenly willing to help!) they reported us to the police because we were murdering our old lady. Some things they said: God has punished you! You show too little understanding! There is a freak in this house! You are paying off your debt! This is an illness! And what will happen when you are ill! Because it's your duty! You should do what she wants! You owe her that! ”- Matsu⁵⁰⁰;

Twenty-four hour care for many years often affects the carer's psychological health. Those people complain about various mental problems. Their tragedy does not often finish even when they stop taking care of the ill, but it continues when the patient is put into care to nursing home:

“Now A. is in a nursing home. We could not stand it. I thought everything would change, however, ummm... I became so terribly indifferent to everything. I can't pull myself together.” –Matsu⁵⁰¹;

Death of the patient:

“The son of my mother went back to work. And me? I was left all alone in an empty house. Then the silence around made me realize that the exam has finished. At the finishing line there was just a deep wound in the heart, and much experience, which cannot be forgotten... and this overwhelming emptiness. ” – Joannap⁵⁰²;

6. 3. How to solve a problem?

Based on the analysis of the situation in the English-speaking countries such as Canada, the U.S. and the UK, it can be observed that there are many websites concerning

⁵⁰⁰ Commed Forum Medyczne [Commed Medical Forum]. <http://commed.pl/alzheimer-vt64796.html> , 10.03.2013.

⁵⁰¹ Ibidem.

⁵⁰² Forum Psychologiczne. Nerwica Depresja Psychologia [Psychological Forum, Anxiety Depression Psychology]. <http://www.nerwica.com/alzheimert7305.html> , 10.03.2013.

Alzheimer's disease. They include extensive sections of online help for caregivers. In this section, we will discuss the ways to provide virtual assistance that function in other countries. We will also address the necessity to create Polish equivalents of websites offering support to those involved in the care of Alzheimer's patients.

On the Internet there are comprehensive guidelines informing users of how to deal with someone who is ill, how to take care of one's physical and mental health as well as how to plan expenses. Such guides are both in text and multimedia form ^{503, 504, 505}

On the Alzheimer's Association website, one can find online questionnaires allowing for an initial diagnosis of the emotional state of the caregiver and a helpline open 24/7 for anyone involved in the care of patients ⁵⁰⁶. People operating the helpline offer support ranging from basic information from cognitive impairment occurring in Alzheimer's disease to emergency interventions ⁵⁰⁷.

Foreign websites also allow for an access to a database of institutions, where one can contact locally in case of problems, both carer's or patient's, which are beyond the capabilities of the caregiver and require specialised care. ^{508, 509}

There are also Internet applications, such as:

⁵⁰³ Alzheimer's and Dementia Caregiver Center. <http://www.alz.org/care/> , 10.03.13

⁵⁰⁴ AlzOnline Caregiver Support Online. <http://alzonline.php.ufl.edu/> , 10.03.13

⁵⁰⁵ Alzheimer Foundation for Caregiving in Canada. <http://www.alzfdn.ca/> , 10.03.13

⁵⁰⁶ Alzheimer's and Dementia Caregiver Center. <http://www.alz.org/care/> , 10.03.13

⁵⁰⁷ Ibidem.

⁵⁰⁸ National Institute of Health. Health & Aging Organizations Directory. <http://www.nia.nih.gov/health/resources/search/alzheimers-disease> , 10.03.13

⁵⁰⁹ MedlinePlus Alzheimer Caregivers. <http://www.nlm.nih.gov/medlineplus/alzheimerscaregivers.html> , 10.03.13

1) Applications enabling the carer to plan his/her future and well as the future of the Alzheimer's patient. The software aims to raise awareness in terms of future needs such as: adaptation of the patient's home, the activity of the patient or driving by car.

2) Calendar, thanks to which caregivers can plan a to-do list of with respect to the sick person, e.g. meals, keeping the patient company or transport by car. With the calendar, one can also easily organize their time with friends or family members with respect to the care time.

3) Virtual library, which contains a collection of scientific publications on Alzheimer's disease⁵¹⁰.

An American association operating under the name of Alzheimer's Association, offers access to multimedia resources, such as educational videos in one of the sections on their website. Users can find speeches of eminent scientists on the important role of early diagnosis in patients with Alzheimer's disease, current research or the effectiveness of some drugs⁵¹¹. In addition, videos including useful tips on how to use a diet rich in antioxidants or which activities and exercises are most beneficial for the patient were made available for those looking for support⁵¹².

When they register on the website, carers of people affected by Alzheimer's disease agree to receive a weekly newsletter created by the association's members. The newsletter contains e-mails with the latest news from the world of science and politics as well as information about new scientific discoveries and governmental action on dementia. In addition, in the electronic newsletter, one can find information about newly formed support groups, trainings for carers of the ill and short thematic workshops such as "the basis of communication with a person affected by Alzheimer's disease"⁵¹³.

Most foreign websites devoted to Alzheimer's allow for virtual contact with people specializing in different types of dementia, e.g. the website of the American Foundation

⁵¹⁰ Alzheimer's and Dementia Caregiver Center. <http://www.alz.org/care/> , 10.03.13.

⁵¹¹ Ibidem.

⁵¹² Ibidem.

⁵¹³ Ibidem.

for Alzheimer's patients have an option called “ask the experts”⁵¹⁴. Specialists provide expert advice on-line and answer questions from those involved in the care of patients, treating each problem individually. A ranking of the most discussed issues and the professional advice by fully qualified people can be found on the webpage. When visiting the website of Alzheimer's Project⁵¹⁵, users can chat online with one of the experts. The above-mentioned options make the flow of information, between the caregivers in need of support and those competent to provide such assistance, fast and very smooth.

Volunteering is an interesting help option. In 1991 the Reverend John Fletcher, pastor of the Methodist church in Florida, introduced an innovative programme to help the needy, which is now known as the Alzheimer's Project. Initially, the range of services provided by the organization was small, and it included support for carers of people with dementia in the parish. Currently the Alzheimer's Project operates in 12 districts of Florida and it brings together people who want to help others.

The main idea of the organization involves looking for volunteers who will be able to provide respite to the caregiver and take care of the person affected by Alzheimer's. Those who wish to provide such assistance, register on a database and sign up for a training session to prepare to perform the future role. Then the volunteer is sent to a family, who have made a request for assistance, in order to accompany the patient for a few hours, and therefore free the caregiver from their responsibilities. Thanks to such services, carers have more time for themselves. The Director of the Alzheimer's Project emphasizes the importance of the caregivers' ability to take care of their own mental and physical condition. The volunteer visits the family once a week and takes care of a patient from two to four hours. The caregiver can devote this time to the pleasures for which they did not have time previously; starting with a long afternoon nap and maybe ending with a long-forgotten hobby. The participants of the Alzheimer's Project define such visits as “the rest time”⁵¹⁶.

Inspired by the complex form of assistance that can be found online in Canada, the U.S. and the UK, one can suggest to create a nationwide portal of a similar type.

⁵¹⁴ Assist Guide Information Services. <http://www.agis.com/community/Ask-The-Experts/afa/default.aspx> 10.03.13.

⁵¹⁵ Alzheimer's Project. <http://www.alzheimersproject.org> , 10.03.13.

⁵¹⁶ Alzheimer's Foundation of America. <http://www.alzfdn.org> , 10.03.13.

Analyzing Polish network resources, one can notice the lack of a properly developed website containing all necessary information on Alzheimer's disease and their carers. This does not mean that such information is not available online. It can be accessed as a virtual guide, found on alzheimer-poznan.pl⁵¹⁷. Creating a comprehensive platform on Alzheimer's patients and their caregivers in Poland is necessary.

Such a comprehensive guide should contain the following information:

- taking care of people with Alzheimer's disease,
- taking care of the health of people dealing with patients,
- Information should be provided both in the text multimedia and form. These should include:
 - taking care of the mental and physical health of both caregiver and patient (what to eat, which types of physical exercises to take, how to lower levels of stress, how to deal with the feeling of loneliness, etc.)
 - financial planning of domestic funds,
 - dealing with an ill person (planning time around the patient, providing them with the maximum amount of freedom and organization of patient's time)
 - problems and impairments that may occur in a patient (e.g. problems with memory).

Including the information concerning medical facilities to help people suffering from Alzheimer's is also important. Thanks to this information carers will save time, which they would otherwise waste on looking for specialists offering the assistance they need.

The site should also provide the opportunity to receive support from a psychologist. Support could be provided either in the form of e-mails in minor cases, or communication by Skype in the event of an emergency concerning the mental health of a caregiver or a patient. Psychological support can also be offered indirectly through a database of therapeutic groups providing support to carers.

⁵¹⁷ Baumann M., Buraczyk M., Knaś R, Przedpelska-Ober E., Rossa A. *Poradnik dla opiekunów osób dotkniętych chorobą Alzheimera* [Guide for caregivers of people with Alzheimer's disease]. Wielkopolska Alzheimer Association. Poznań 2008.

Apart from support by a psychologist, the reduction of stress and loneliness can be provided by a discussion forum for carers. Contact through a forum with others who deal with Alzheimer's patients will allow for:

- exchange of valuable information and tips
- receiving support from other caregivers,
- improvement of mental health due to the altruistic help of other caregivers,
- finding out that caregivers are not the only ones with such a problem.

And can the idea of the Methodist pastor from Florida be used and adapt for the Polish context? It would be worth creating a web portal that, apart from containing educational and informational materials, would bring together people who want to help. That is, volunteers from different regions of the country would be entered into an electronic database of people offering support to families and patients with Alzheimer's after they have registered (entering the place of residence would be necessary for such a registration). An online search system would enable carers of patients to find volunteers in their neighbourhood. Such a project could involve people active in parish associations, or psychology and nursing students.

Summary

In light of the information presented here we can see that the care of people suffering from Alzheimer's disease requires a lot of physical and mental dedication. The requirements that have to be met by carers change from day to day. Carers have to make major changes in their social life e.g. abandon current activities and adjust their free time to the requirements of the patient. Carers may apply a long-term strategy to gain sufficient knowledge, which will be useful for the daily care of the patient. Family educational programmes on the stages of Alzheimer's and practical strategies for dealing with difficult situations provide significant help. Adapting to new challenges, skills gained through experience and strong support from one's family can significantly help caregivers in their daily care of relatives. Support groups are also an important element in the day-to-day lives of caregivers. They allow participants to take a break from daily responsibilities, express their doubts, exchange experience, seek advice and receive emotional support. Self-help networks can be particularly important when caregivers face difficult decisions and they do not know anyone they can turn to for help. Diagnosis of the disease poses a

lot of questions for people, the answers to which are often difficult. Obtaining reliable information is not possible or not helpful enough in a given situation. Problems concern not only the patient themselves but also financial costs, security, legal advice and future planning. Caregivers also have to remember about their own health. A balanced diet, physical exercise and stress reduction methods are important factors. In the era of new online technologies there is a need to create a platform which would bring together carers of people with Alzheimer's disease. By analyzing forum posts we can observe a great need for a uniform information service which would provide useful knowledge from professionals. But most of all, the most important tasks of the platform should include the creation of a community of carers and patients. It should be a community formed on the basis of reliable knowledge on which its members would be able to rely with confidence. This would ensure the necessary level of support and assistance needed to work with patients. Moreover, it should be a platform where carers would be able to read the latest news about knowledge of this disease and the development of methods of inhibiting its progress. It should bring together volunteers and allow them to access information on people seeking help. In the longer term, it should coordinate volunteers with people seeking help so that it was a place where caregivers could request volunteer help in real life. Finally, it would have to provide information on local centres and support programmes for carers and patients. We hope that in Poland, following the excellent example of the Western countries such a professional platform for supporting carers responding to their needs will also be created.

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7.3 Dementia in a Danish perspective

It is estimated that approx. 87,000 Danes currently suffer from dementia (2013), and as a result of the growth in the proportion of elderly in the population, the number is expected to increase to approx. 130,000 in 2030, ie. an increase of just over 50% in less than 20 years. Furthermore, according to figures from the Danish Dementia Research Centre it is estimated that approx. 15,000 Danes annually develop dementia. This number is expected to increase accordingly (1).

In 2010 a set of national guidelines for the dementia effort in Denmark were developed (2). The guidelines were based on recommendations for the future work carried out by an expert group. These guidelines form the basis of the dementia care in Denmark regarding both treatment and social care and virtually all of the recommendations have been launched in practice. One of the recommendations were specifically aimed at the use of psychosocial methods:

"The expert group recommends that a greater effort is made to seek for and systematically gather information about the use of different psycho-social methods, and that there is an increased systematic coordination of the experience with psycho-social interventions" (2).

National clinical guideline on dementia

In 2013 - following the recommendations in the national guideline - a national clinical guideline for diagnosis and treatment of dementia has been prepared and it is currently in a state of hearing, hence, it has not yet been approved (1).

The guideline is expected to contribute to an evidence-based approach of consistently high quality across the country, to ensure continuity of care and to ensure knowledge sharing across sectors and professions. The guideline covers the various phases of patient care, including assessment and diagnosis, non-pharmacological interventions, pharmacological treatment as well as efforts aimed at the relatives.

The recommendations regarding non-pharmacological interventions are:

- *It is recommended that people with dementia living at home as well as in nursing homes are offered maintenance training of daily activities*

- *It is recommended that people with dementia are offered physical activity and physical training*
- *It is recommended that people with dementia in mild to moderate degree are offered cognitive stimulation*
- *It is recommended that professional caregivers working with people with dementia is organized in multidisciplinary teams*
- *It is recommended that relatives and caregivers are trained and supported in providing behavioural changing efforts to the demented person*
- *It is recommended that people with dementia is offered regularly access to day care and thus relieve the relatives*

Dementia care in Denmark

The recommendations mentions specific areas that should be in focus in the future and virtually all the recommendations have been launched. The responsibility for treatment and care of people with dementia is divided between the five regions (hospital level) and the 98 municipalities. However, there is no firm agreement on how dementia care should be organized. The dementia care is based on the Legislation on social services that in this case works as a “framework law” that only dictates what the municipalities and regions are obligated to ensure - but not how it should be implemented. More often the regions have the responsibility for assessment, diagnosis and specialized treatment, while municipalities carry out the daily treatment and care (3).

Care for people with dementia is a task that involves the municipal sector, the hospital sector and the private physicians. In terms of both of the dementia diagnosis and the organization of care - assessments and contributions from several different professional groups are needed. It specifically involves caregivers from the municipal home care, assisted living facilities and hospital dementia units, physicians in general practice, municipal dementia consultants and dementia coordinators, social workers, occupational therapists and physiotherapists, home tutors and psychologists (mostly neuro- or geronto psychiatrists) (3).

Cooperation in the interdisciplinary teams is organized in several ways. One example is the interdisciplinary geriatric clinics and geronto psychiatric teams established in

hospitals - or dementia teams that may be established in both hospitals and municipalities (4).

Cooperation in interdisciplinary teams serves several purposes (4):

- coherence and continuity of care
- involve multiple perspectives and professional skills in working with dementia
- support people with dementia and rehabilitation activities
- accommodate the needs of people with dementia from a holistic perspective

Housing

A study has shown that in Denmark approx. 85% of people with dementia live at home either alone or with one or more of their close relatives (5). These persons are often in an early stage of dementia and can be cared for by their relatives. People with dementia living at home are entitled to receive help from the municipal care services according to their functional level and the Danish study showed that approx. 55% receive home care (5). However, a Danish project from 2010 showed that more than half of the relatives had to give up one or more of their activities of daily living (6). Another study showed that being a caregiving relative for a person with dementia took its toll both physically and mentally in the form of increased risk of developing depression and stress, and that they had a higher mortality rate than others (7).

When it is no longer possible or desirable for the person with dementia to live at home he or she will be offered to move in to a public nursing home in the local municipality. In Denmark the municipality is obligated to find an opening at a nursing home no more than two months after the need is identified. Furthermore, the municipality is required to make an accommodation available where the couple can live together if it is desired (8).

The vast majority of the Danish municipalities have specialized units aimed at persons with dementia which is called shielded units (9). A shielded unit is a smaller specified unit of convenient limits, with a small number of fellow residents and permanent and well educated caregivers. The purpose of shielded units for people with dementia is to create a safe environment that uses psychosocial methods in the care and management.

Materials and Methods

Materials for this report have been located through Google.dk and similar search tools as well as through Danish official websites. The search has been conducted in May to July 2013. The websites include among others “Danish Alzheimer's Association”, “Danish Dementia Research Centre”, “The Ministry of Social Affairs”, “National Board of Social Services”, “Danish Health and Medicines Authority” and “The Danish National Center for Social Research”. Furthermore, the various municipalities’ websites have been included. In addition, materials have been located through chain search in reports and articles. Main search terms included the Danish version of “psychosocial methods”, “non-pharmacological methods”, “dementia”, “relatives”, and “caregivers”. The report is primarily based on Danish projects and reports mainly from national centres and organizations.

Psycho-social methods in Danish dementia care

Since the early 1990’s dementia care has been based on a psycho-social approach where the behaviour of the person with dementia is seen in a broad perspective, which is why different perspectives and academic approaches are combined (10). In this perspective the demented person's previous personality and life story are involved, as well as the brain damage caused by the dementia disease. The brain damage depends on the particular type of dementia and stage of the disease. Furthermore, other diseases, possible side effects of medical treatment and the person’s interaction with other people and the surroundings are taken into account. The aim is to improve the demented person's well-being, and enable the person to remain in the early stages of dementia as long as possible (10).

Reminiscence

Reminiscence is a widely used method in Denmark and it refers to recollections of memories from the past (3,4,10). The purpose of reminiscence is to strengthen the identity, integrity and sense of continuity. If objects (triggers) that stimulate the senses are introduced, it is more likely that the person can evoke memories. The aim is to move from abstract conversation about a topic to tactile and visual stimulation all of which can evoke memories that the person with dementia is assumed to have in relation to the object.

The technique can be used both individually and in groups with the aim of eliciting and

sharing pleasant memories and experiences in an informal and conflict-free manner. Reminiscence is believed to be beneficial in all phases of dementia (11).

Life review

The methods of life review and reminiscence are related and the two methods are often described interchangeably (10). But where reminiscence is often spontaneous memories, the life review is a more structured form of recall, organizing and evaluating a personal life history. Hence, life review is a therapeutic process in which the individual seeks to achieve a realization of his own life and accept the importance and impact it had on the formation of his identity. The purpose of the life review is to reach an understanding and acceptance of life. For this purpose written or taped self-biographies, reunion with former places and people either in person or through correspondence, family trees, scrapbooks and photographs can be used (10).

In Denmark the term “life history” is more often used which is a non-therapeutic method to create a systematic overview of a person's life. The purpose of this overview is to support the person with dementia to recall and retain their memories as long as possible. Furthermore, the purpose is to gather information on the person with dementia and thereby form a basis for working with reminiscence, gentle teaching and reality orientation. The life history can address events and experiences that relate to a specific time, people and places. The life history can involve both facts and subjective memories of the person. Facts can be names and places or a description of a working life. Or it may be the person's tale of the people and family members, opinions and moods that have been most significant - a story about a person's achievements, feelings and opinions (12).

Validation

The starting point of the validation-method is that all behaviour carries a meaning and that although constructive thinking deteriorate with dementia, feelings and content remain. Therefore, the professional caregiver must recognize the value and the validity of the demented person's experience in order to achieve better contact and a more profitable relation. Validation is a reflection of the person's feelings in order to help the person with dementia to express unmet needs and to rebuild established social roles. The

objective is to induce well-being, reduce uncertainty and conflict, and to stimulate interaction with others (10).

Reality Orientation

Reality Orientation, RO help the person with dementia to orientate themselves in everyday life. The target population is people with mild to moderately severe dementia and the technique can be used both in groups and individually. RO or “correction” may be relevant in connection with disorientation and disturbed circadian rhythm (4).

The idea is that people with dementia repeatedly receive information on time, place and people with the aim that they will have a better understanding of the surroundings and it may also increase their sense of control and self-esteem. The method includes RO-board, clocks, calendars (manual and electronic for Ipads etc.), cards, posters, materials to stimulate the five senses, repetition of orientation, cooking, drawing exercises, associations with words, naming objects, gymnastics etc. (13).

Marte Meo

Marte Meo is a method where the interaction between the caregiver and the person with dementia is recorded on video. Video recordings form the basis of an analysis of the interaction, and can be used to visualize functional levels of a person with dementia. The caregiver uses the method to adapt the communication and the daily care in relation to the resident. The intention of the method is to identify the type of communication that is best to support the person's own resources, making the interaction as positive and conflict-free as possible (3). Furthermore, Caregivers become aware of their own resources and will be able to use and develop these resources in interaction with other people. Although the approach is beneficial for caregivers, it is not however without hindrance. Not everybody likes to be recorded on video, and it requires confidence within the group of caregivers in order to test the method and develop experiences in a safe setting (14).

Gentle teaching

Gentle Teaching, GT can be described as a heart-oriented relational psychosocial method where the caregiver uses himself or herself as a tool. It is primarily used in care for people with developmental impairments but it is also used in dementia care. The

fundamental aspects of GT are safety, acceptance, connection, togetherness and interaction – and it is based on the emotion behind the patterns of reaction that we encounter, instead of focusing on the concrete reaction or behaviour. GT consists of four basic principles in the everyday practice: that the resident should feel 1) safe, 2) loved, 3) capable of loving others, and 4) committed. GT also include gently pushing the resident to the edge of his or her abilities, to challenge the resident on his or her terms and avoid having the resident to go to the edge with the feeling of being alone (15).

Retrogenesis

Retrogenesis is defined as the process by which the degenerative processes in the brain deplete what has previously been learned. Various studies on the brain have demonstrated that several elements of the degeneration in the process of dementia correspond to the inverse process of the development that occurs through childhood. This knowledge can be used both in the understanding of the emotional change in the person with dementia and in the organization of the general care and activities around people with dementia (10).

Multi-Sensory Stimulation (Snoezelen)

Snoezelen is an individual activity where several senses are stimulated by sound, light, smell and other sensory objects. The method is based on an emotional and non-intellectual interaction, thereby providing experience and comfort in a relaxing and comfortable atmosphere and is especially used in the care for severely demented people. The tools may consist of music systems, light projectors, fibre optic lights, smells and objects that moves when they are touched, objects that feels different (e.g. pillow that vibrates when it is hugged, pillow or duvet filled with small balls) (10).

Music and dance stimulation

Music and singing are part of the social educational work with people with dementia. Music and singing have for many people a unique ability to evoke emotions and memories. Advanced dementia often impairs the language skills, but some of those who lose the language as a result of dementia are still able to sing. Others are in spite of the pronounced memory impairment able to remember the lyrics, keep a rhythm or play an instrument. Singing in some cases constitute the final language of expression in severe

dementia (3,4,10). In addition to music stimulation music therapy is widely used in Danish dementia care with the purpose of reducing neuropsychiatric symptoms that would otherwise often lead to medication. The key to cover psychosocial needs is to provide recognition and regulate arousal through music (16).

Person-centred care

Person-centred care aims to make the care and nurturing environment personal and individual and to understand behaviour and psychiatric symptoms from the perspective of the person with dementia. Person-centred care is based on information about life history, habits, values, needs and preferences. Person-centred care also means that one is aware and respectful of the special needs of people with different cultural or linguistic background (4,17).

Social pedagogical methods

Social pedagogical methods are the main academic approach in work with people with dementia, and it follows directly from Danish legislation that social pedagogical methods always must precede the use of force. The purpose of social pedagogical methods is to support that a person with dementia remains an authoritative, self-determining human being. Social pedagogical methods aim to help the person with dementia to live a life that makes sense for that person and contains meaningful activity. One of the caregivers' social pedagogical tools for making contact is to offer so-called 'contact pads', by which is meant a structured activity offered in the same manner and with the same sequence every time. It can be certain rituals, routines or activities, readings or songs. After some time the person with dementia will often learn the pattern and the contact can help to reduce inappropriate behaviour (3).

Other non-pharmacological methods

Animal Assisted Activities

Several Danish nursing homes have good experience in keeping pets such cats or dogs. Pets can create a good mood, alleviate anxiety and provide persons in all stages of dementia with an opportunity to show compassion. Pets provide variety in everyday life, they give rise to conversation and the elderly have a living creature to care for. They are

a source of spontaneity and something to follow both physically and mentally. The most common animals are birds, cats and dogs, but also rabbits, chickens and fish can be used (4).

Furthermore, a large research study has recently been completed regarding the impact of visit dogs in Danish nursing homes (18). A visit dog in this context is a privately owned dog that regularly comes to visit with his owner. In April 2013 there were approx. 200 certified visit dogs in Denmark. It is the first time that a comprehensive research of the effect of different types of visits to elderly people and people with dementia has been conducted - in this case visit dogs, robot seals and dementia dolls. 100 residents from four specially selected nursing homes in a Danish municipality participated in the three-year research project. The preliminary results showed that it is easier for older people and people with dementia to establish contacts to visit dogs than to robot seals and dementia dolls (18). However, the final results have not yet been published.

Technology

In recent years, technological developments have produced cuddly robot pet as Paro the seal, and preliminary experiences in relation to dementia is positive. Paro is a Japanese developed model of a real baby seal. It is designed so that it looks like, reacts and moves in the same way as a real seal. Denmark is the first country in the world to target working to professionalize the use of welfare robots like Paro by training and certifying caregivers.

In June 2012, there were about 240 Paros in Denmark and the idea is to complement, enrich and support the caregiver's professionalism with an additional tool or approach. The seal robot may very well be an addition to live animals and dolls for people with dementia (19).

In many nursing homes so-called dementia dolls are used. In some persons with dementia, a doll arouses compassion and eases the communication. A lot of elderly people with dementia still have a great need to provide care and this need is awakened when the person meets the dementia doll. The dolls have the same size as an actual baby and the soft fleece body gives the feeling of body heat. The weight is vivid and it is able to sit well on the lap. In recent years it has in been shown through research both in Denmark and abroad that the dementia dolls may in some cases help the person with dementia to calm down and feel happy and secure. The dolls are primarily useful in

severe stages of dementia and it needs to be used with consideration as not all people with dementia and their relatives will find it appropriate for adults to care for a doll (17).

Maintaining activities of daily living

Practical, everyday chores such as shopping, cooking, cleaning, laundry and garden work can be difficult or confusing for the person with dementia even in the early stages of the process. This is especially regarding the cognitive difficulties, including weakening of initiative and determination that characterizes most dementias. Sometimes relatives react by taking the initiative and taking over most activities causing a risk that the person with dementia slip into a state that 'learned helplessness'. In this state another has taken over everyday activities that the person with dementia could be able to maintain with just a little support. The problem can to some extent be prevented by making the relative and the person with dementia pay attention to it. Alternatively, a municipal employee who regularly come into the dementia home, help systematize the practical everyday chores and support the person with dementia in continuing activities and hobbies as long as possible (4). There is evidence that participation in social and leisure time activities may have some preventive effect against the development of cognitive impairment (20,21).

Physical training and exercise

The aim of physical exercise for people with dementia is not only to improve functional capacity, flexibility, circulation and fitness, but also to support the sense of identity. Bodily changes may threaten the identity. A focus on the body decrease the risk of loss of identity in the same way as described for loss of meaningful activity. The two problems can reinforce each other. Actual fitness training involving machines and tools like treadmills and dumbbells will usually only be beneficial in the early stages of the dementia process. However, already learned physical activities may be preserved well into the process - for example sports. Later in the process, the physical training may take the form of physical exercise or play, where the focus is also directed at stimulating the senses, balance, responsiveness and alertness (4).

Danish Alzheimer's Association – Folk high school

The Danish Alzheimer's Association has launched a new four-year folk high school project to help people with dementia remain active and maintain a social network. The

Danish folk high schools offer non-formal adult education in a social environment with residential facilities.

These specific courses are aimed primarily at younger and early diagnosed persons as the person should be self-reliant and able to care for themselves - e.g. get washed and dressed in the morning. The courses typically involve physical activities as dancing, running, ball games, choral singing, lectures and gatherings. Dementia specialists arrange and participate in the courses and the days are organized so that they take into account the participants' strengths and weaknesses (22).

Psychosocial methods aimed at both the person with dementia and their relatives

Dementia is characterized by not only affecting the person with dementia, but the whole family and especially spouses and (usually) adult children. In addition, many healthy relatives deliver a great effort in relation to the maintenance of the home and care for the person with dementia and therefore need to gain knowledge about the disease.

Furthermore, it is very important that the caregiving relative is supported and encouraged to maintain the everyday life (23).

Psychosocial methods aimed at relatives are also included in the national clinical guideline on dementia that is currently in a state of hearing (1). The recommendations are:

- *It is recommended that caregiving relatives are offered psycho-education in groups*
- *It could be considered to offer customized training of more than six sessions duration for caregiving relatives in the management of Behavioural and Psychological Symptoms of Dementia (BPSD)*
- *It could be considered to offer training of care-giving relatives in coping strategies*
- *It could be considered to offer cognitive behavioural therapy for caregiving relatives*
- *It could be considered to offer personal advice and support for caregiving relatives who have personal difficulties that complicate the relationship with the person with dementia*

Intervention in the form of counselling, physical relief and support to the relatives are widely used in the Danish municipalities, as 95 % of the Danish municipalities offers special interventions for relatives (24). Virtually all municipalities have dementia coordinators or consultants whose function consists in being knowledge persons on dementia and ensure targeted dissemination of the options and activities the municipality offers to people with dementia and their relatives. In addition, several dementia assessment units, hospitals and volunteer organizations, such as the Danish Alzheimer's Association, provide counselling, social activities and education to people with dementia and their relatives. In this case relatives may be spouses as well as adult children (3).

Relief to the caregiving relative

In addition to the psychological support most municipalities offer some sort of practical support and relief to relatives who are co-living with a person with dementia. A Danish report on the needs of relatives to a person with dementia showed that 1/3 of the persons with dementia living at home are unable to take care of themselves if they are left home alone. This means that a significant part of the caregiving relatives have to give up meaningful activities and stay home with their husband or wife (23).

For this reason, 72 % of the Danish municipalities offer relief to the caregiving relative in their own homes in greater or lesser extent (24). “Relief at home” can relieve the relative and the duration may be from a few hours a week to around the clock. This system allows the relatives to participate in activities on their own and relieve them from the responsibility for a while. Furthermore, the relative can be relieved through professional personal care for the person with dementia as well as practical help around the house.

Most municipalities cooperate with voluntary organizations, which can provide “relief at home” and respite for caregiving relatives of people with dementia. Relief provided by volunteers may include participation in daycare centres/activity centres and “visit friends”. A visit friend is a volunteer who visits the person with dementia on a regular basis offering a time to talk or perform simple activities together (23).

If the person with dementia is below 67 years of age he or she can be granted with a “companion” – a professional follower - who can transport and accompany the person with dementia to activities of interest in order to maintain an active life (23).

Day care and temporary residential facilities

In addition to “relief at home” all municipalities offer day care in various forms but not all municipalities have special offers for citizens with dementia (3). The day care centres serve two purposes as they relieve the relative as well as bringing social and physical activities to the person with dementia. The overarching aims of most public day care centres for people with dementia are to enable the person:

- To continue physical and interest-based activities
- To maintain intellectual and practical abilities and skills
- To experience a safe environment in a social community with others in a similar situation

Approx. half of the municipalities have temporary residential facilities with educated staff where persons with dementia and other physical or mental dysfunctions can stay for one or more nights offering the relative a break from the responsibility (24). These houses can also be used in case the relative is ill or hospitalized.

Counselling and support groups for relatives

The vast majority of the Danish municipalities (90 % in 2008) provide “relatives groups” as well as individual counselling and guidance (3). The purpose of these groups are usually to give advice and support and build up a network, where the caregiving relative can talk with other relatives who experience similar situations. This also gives an opportunity to exchange knowledge and experiences. There is commonly a professional caregiver present who may help answering questions and provide advice and support. The relatives groups typically contain therapeutic elements such as sparring, mirror methods and conversations between participants and dementia coordinator. The groups often have a fixed time and day of the session. The overarching aim of groups for relatives is to provide the relative with tools to help master difficult situations in everyday life. Another advantage in support groups is that the relative can experience

that he or she is not alone with these problems and that they can share their joys and sorrows with people in similar situations (3).

As a fairly new initiative support groups for young relatives are starting to emerge targeted at children and young adults with a parent suffering from dementia. Children and young adults often find themselves in other situations and problems than spouses which means that they do not fit in to the conventional support groups (25).

Education

Newly diagnosed persons with dementia and their relatives are often offered to participate in some sort of education about the disease, the typical course of disease, treatment options, options for help and support, and how to protect their personal and financial interests in the future (4). Approx. 2/3 of the Danish municipalities provide proper education for people with dementia and their caregiving relatives. This education is planned very differently in the various municipalities and rates from a single afternoon to long-term courses (9).

Practical education for relatives – an example

Dementia Centre Aarhus successfully completed the first module of education for relatives of people with dementia in the spring of 2013. They continue with module 1 and 3 in the fall of 2013. The education program is unique in Denmark because it targets the practical everyday life living with a person with dementia. The program focuses on enabling the relative to take conscious decisions about how to care for the person with dementia.

Each module is followed by individual guidance and a question hour once a month to help the relative master the difficult process it may be to translate new knowledge into practice and change behaviour in everyday life. The program is aimed at family and close friends of a person with dementia. The education program consists of three modules related to the phases of dementia. The modules are offered sequentially and independently.

- Module 1: Dementia in mild degree: The cognitive impairment causes only slight deterioration of performance in everyday life.

- Module 2: Dementia in moderate degree: The cognitive impairment results in a substantial deterioration of performance with greater challenges in everyday life as a result.
- Module 3 Dementia in severe degree: The cognitive impairment means that the person is totally dependent on help from others and is usually moved to a nursing home.

Each module has duration of three hours per week in four weeks (26).

Dementia café

Café Meetings is a Dutch idea that has also been widely established in Danish municipalities. The meetings are held in informal settings, where persons with dementia and their relatives meet and talk openly about their situation. Café meetings may be preceded by an academic paper as the basis for a joint discussion (4).

A dementia café is typically an open offer which means that everybody can participate regardless of their current situation. The cafés aim to create space and social activities for people with dementia and / or their families, as well as volunteers and other interested persons.

The café allows for a good talk, but most important is being together with others in similar situations. Professionals usually participate in dementia cafés and can help answering questions about the dementia disease and everyday life (27).

Written and electronic information

Education targeted at people with dementia and their relatives can be supplemented by provision of written information. As with education, it is essential that the material available is tailored to the needs and capacities of people with dementia. One advantage of the written material is that the person with dementia can read and study it as needed in peace and quiet. For a person with impaired memory written information is often a good addition to the oral information (4). The primary organisations that provide written and electronic information include the National Board of Social Services, Danish Dementia Research Centre, Danish Alzheimer's Association and the individual municipalities. The topics consist mainly of knowledge about the dementia disease (prevention, symptoms,

treatment etc.), legislations and legal aspects, social services, psychosocial methods and everyday life with dementia.

DAISY

The Ministry of Social Affairs, the National Board of Social Services and Danish Dementia Research Centre have carried out Denmark's only major scientific study of people with dementia in the recently diagnosed stage (28). The study is called DAISY (Danish Alzheimer Intervention Study).

The DAISY-project examined the effect of an intensive program of support for people with dementia at an early stage and their relatives. This resulted in the development of a counselling model that was developed as a professional tool in the counselling work. DAISY's model of counselling and education are targeted persons with dementia in the early stages of the disease and their relatives. The model focuses on strengthening the positive elements of the lives of the person with dementia and the relatives according to their own wishes and values. The model provides a practical guide to implementing consultancy and training for people with dementia and their caregivers, e.g. in hospital units and municipalities.

The model is based on the following principles:

- Focus on the person with dementia
- Involving the network of relatives and close friends
- Counselling
- Dialogue-based conversation
- Education

The intervention program includes individual counselling, group counselling, network consulting and telephone counselling. Moreover, the model contains participation in a series of courses as well as written information aimed at people with dementia and their relatives. The model has also been useful in several municipalities outside the project where it has been implemented as part of the general dementia effort (28)

Herning – an example of a Danish Municipality

As previously described not all municipalities provide all of the above mentioned efforts aimed at relatives to people with dementia. In the following section the efforts of a typical Danish Municipality is described.

The Dementia team

The dementia team in the Municipality of Herning consists of two dementia consultants and two dementia supervisors. The Dementia consultants are responsible for support and guidance on nursing homes and for people with dementia living in their own home as well as for caregiving relatives.

The dementia team offers:

- Coordination of efforts for families affected by dementia, in order to create coherence in the intervention
- Individual counselling of both the person with dementia and the relatives
- Relatives Groups
- Education
- Cooperation with physicians
- Cooperation with dementia units
- Guidance on the municipality's offers and efforts
- Working with volunteers
- Special activities offered to people with dementia
- Dementia School for relatives and people with dementia
- Study groups for younger people with dementia and their relatives
- Providing guidance to other health professionals about dementia

Visit friends and relief to relatives

The Municipality of Herning offers visits to people with dementia and relief for relatives in close cooperation with the volunteer visit friend services and relieve services. It is possible to get a visit friend from the five organisations. Visit friends from these organisations have been trained in dementia by the dementia consultants. They also participate in activities for people with dementia and their relatives.

The Dementia Club

The dementia club is an offer to younger people with dementia and it is open every Friday from 9:30 to 13:30 on the “Active Centre”. There are also club nights where spouses can participate in activities.

Relatives Groups

A support group provides an opportunity to meet with others in a similar situation and exchange experiences. Conversation topics will include:

- Knowledge about dementia and the process of the disease
- Opportunities for support in the municipality
- Life Story

At the same time, it is possible to:

- Share joys and sorrows
- Help each other
- Strengthen the acceptance of the new life situation
- Find opportunities in the new situation

Safety and trust is important in a support group, and it should be a sanctuary where the relatives can unload and say just what they need. There is confidentiality within the group.

The aim is that the participants in the group increase their mental, physical and social well-being. Each group will be composed by the dementia consultants following an individual interview.

Activity Centres and Activity Houses

When a person is more than 60 years of age or early retired he or she may join a number of Activity Centres or Activity Houses in the municipality. The Activity Centres offer activities, training, personnel assisted activities and professional day care. In Activity Houses activities are primarily created and run by volunteers.

A sense of community is the most important issue in both centres and houses and the activities are organised and carried out by the users themselves. The purpose is to offer

opportunities of activity for all users and help to create networks and strengthen the volunteer work. Users and caregivers collaborate in each individual centre or house.

Odense – an example of a Danish nursing home

Enrum is a nursing home only for residents with dementia. It is one of Odense's smallest nursing homes with 22 permanent residents and two temporary residents. The caregivers are well trained and they are present around the clock.

The main focus lies on working with the five senses as well as with activities of daily living.

The specially trained activity staff strolls with the residents, work with memory boxes as a part of reminiscence and attend coffee clubs. The volunteers also stroll, bake and read with the residents. Furthermore, Kikki the Clown entertains every 14's day and there is a musical feature approx. once a month. There is a confined sensory garden with fruit trees, fragrant plants and colorful flowers which is used extensively in the summer. In the garden there is a sensory swing and opportunity for a nap under the fruit trees. All in all, there is peace, routines and regularity (29).

Summery

In Denmark the dementia care is based on the Legislation on social services. Approx. 85% of people with dementia live at home either alone or with one or more of their close relatives. The remaining 15% primarily live in public nursing homes.

Since the early 1990's dementia care has been based on a psycho-social approach and the most widely used psychosocial methods aimed at the person with dementia include reminiscence, life history, retrogenesis, multi-sensory stimulation and music stimulation. Efforts aimed at the caregiving relative include education, support groups and regularly relief of the responsibility.

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8. The data from qualitative studies and interview with physicians and other professionals caring for patients with dementia

8.1. Physicians

We planned to administer the questionnaire to a group of twenty family doctors and neurologists. Our aim was to gather information about the characteristics of caregiving for people with dementia. To achieve this goal we used questionnaires which had initially been prepared to collect information on the level of knowledge about the disease in unprofessional dementia caregivers, their care recipients and their families. We received back only five out of twenty questionnaires that were sent to physicians, in many cases, respondents refused to participate in the study after they had read it. In contrast, physicians would have been eager to participate in the study had it included professional and precise questions designed for their professional group.

All respondents paid attention at organizational issues, scarcity of time to deepen the relationships with patients, difficulties in communication with the families, demanding attitude of caregivers and their expectations for a miraculous recovery". Physicians also reported their feelings of helplessness facing the illness and stated caregiving for someone with dementia was difficult. Specialist physicians expected family doctors and social workers to become involved in medical care for someone with dementia because presently they could see no involvement on their part.

8.2. Nurses

The study of nurses was carried out in the Province of Wielkopolska and in the city of Poznan in neurological and internal wards. All nurses participating in the study attended a specialist course in neurological nursing. The questionnaires were provided and collected directly by the researcher.

All nurses (n=10) are satisfied with caring for their patients. They find it most difficult to communicate with them (as reported by six subjects). Additionally, the therapist's work was facilitated by nursing care (2), cooperation with patients (2) or

others. The nurses also reported sources of their knowledge about the illness such as the Internet, experience or professional literature (6).

All subjects declared the patient- therapist relations were either correct, good or very good. Almost all respondents (six out of seven) were worried by the advancing illness of their care recipients, were supported by their family and caring for patients was not in conflict with their private and professional lives. One participant left the two latter questions unanswered. Most respondents (six out of seven) reported they were helped by other staff members with a division of duties. Only one person reported not experiencing emotional burden resulting from the work with demented patients. Nurses believed that patient care would be improved if they had more time or better medical equipment (2), more specialist and a special rehabilitation program designed for these patients (3), if the family were more involved (1) and there were more extra activities such as community clubs to facilitate patient's physical and psychological activity and their social relations. They also noted social isolation was one of the biggest problems for patients. Because of this, patients would spend many hours in bed during the day although it wasn't necessary for people with their health status.

Nurses could also observe that death was what patients feared most. They also paid attention at significant financial problems experienced by patients' families which limited their chance of participating in additional rehabilitation classes. Also, they believed rehabilitation financed by the National Health Fund was insufficient.

8.3. Physiotherapists

The survey among physiotherapists was carried out in the Province of Wielkopolska and in the city of Poznan in nursing institutions where ill people such as dementia patients are institutionalized mainly in a Catholic – run St. Vincent a Paulo Nursing Home at Sielska Street, nursing ward of a Regional Health Center in Wolsztyn, in a government – run Nursing Home at Mińska Street and at a Stroke Ward of Jan Strus Hospital at Szwajcarska Street. We were refused to carry the survey at the Public Nursing Homes at Bukowska Street and at Konarskiego Street.

The institutions were selected randomly, and then the requests to carry the survey were made either personally or by the phone. After the date of the meeting was arranged, the physiotherapists were directly given the questionnaires by the researcher. .

All physiotherapists participating in the study claimed that working with demented patient brought them satisfaction. They declared that they chose the profile of their work voluntarily. Moreover, most of them (seven participants) reported they had friendly relationship with their patients. Various difficulties associated with working with demented patients are presented on Figure 1 below.

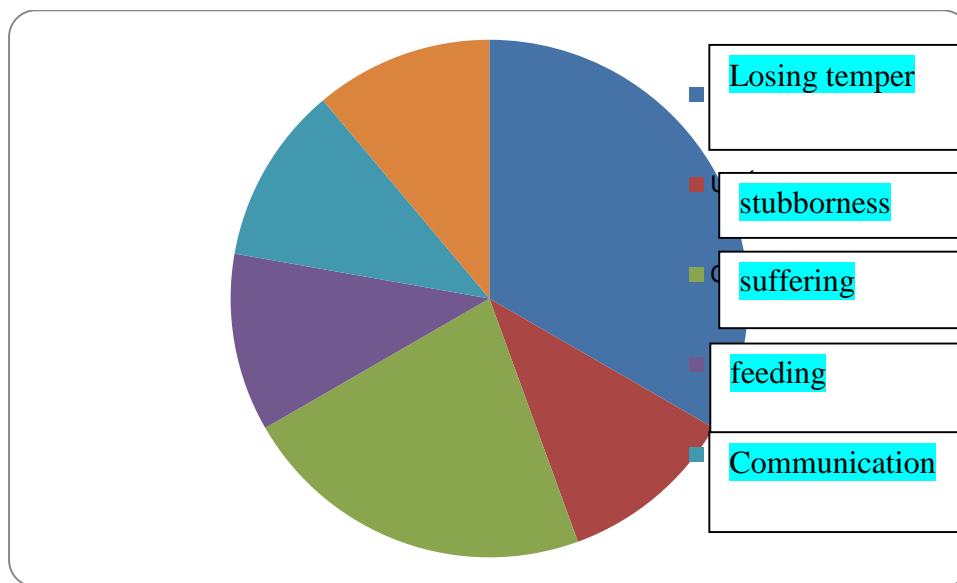


Figure 1. Difficulties reported by physiotherapists caring for demented patients.

Source: author's materials

Four physiotherapists in the study gathered information about the illness from other staff members, particularly from the supervising doctor and from the Internet. The majority of participants of the study (seven of them) were worried by patient's advancing illness.

Eight physiotherapists maintained that while working with demented patients they received support from their families and their job was not an obstacle to their private lives. Six physiotherapists in the study declared they were supported by their colleagues i.e. by

the nurses, physicians, ward sister or occupational therapists. Most of them said there was a division of duties in the ward.

They also believed that the following conditions should be met to make working with patients more effective:

- There is more personnel for individual nursing care (four people)
- Home care and rehabilitation should be reimbursed by the National Health Fund more often. (1)
- There is more help from the government (1),
- There is more empathy (2)

*1 participant of the study left the question unanswered

9. Final conclusions for the platform

Early detection of disability in the elderly makes it possible to implement a more efficient intervention so there have been attempts to find an accurate tool to monitor functional status among senior citizens and their caregivers. The analysis showed that females needed aid mostly in the following domains i.e. health; mental health and wellbeing and looking after ill persons and yourself . Difficulties in performing tasks in these domains were also found in many articles in Poland and other countries also.

However, if the caregiving staff focuses on health and care over family members with dementia these issues too much, other areas of life for example looking after yourself may become neglected. According many research such situation was observed in many countries.

That is why the platform issues should include:

- Information on dementia, its types, symptoms and means of diagnosis.
- It is necessary to prepare a set of cognitive rehabilitation exercises which can be practiced with the help of non – professionals at patient's home.
- Make it possible for caregivers to communicate with professionals on line.
- Use the platform to facilitate communication between caregivers
- Prepare a data base of institutions with professional staff.
- Caregivers need informational support on additional on-line questionnaire enabling preliminary diagnosis.
- Information on how to deal with the affected patient.
- Information on how to care about one's physical and psychological care.
- Information on how to budget expenses, schedule therapies, e.g. a diary where appointments, treatment plan and drug administration can be put down.
- Publications on dementia, caregivers and their problems.
- Information on medical centres where dementia can be diagnosed.
- Information on available educational programmes.

- Information on equipment useful/necessary for caregiving and possibilities of purchase and reimbursement thereof.
- Information on available methods of motor and cognitive therapies.
- Information on already existing (also virtual ones) support and therapeutic groups.
- Information on volunteers who are ready and willing to help.
- Information on aid institutions and organizations.
- Information on existing care centres.
- Legal advice on medical certificates, sick leaves, and bailout.
- Information on contact telephone numbers of doctors, psychologists, nurses and social workers available 24/7.
- Online for a for caregivers - educational movies including experts' advice.
- Applications enabling the carer to plan his/her future and well as the future of the Alzheimer's patient.
- The software should aim to raise awareness in terms of future needs such as: adaptation of the patient's home, the activity of the patient or driving by car.
- Calendar, thanks to which caregivers can plan a to-do list of with respect to the sick person, e.g. meals, keeping the patient company. With the calendar, one can also easily organize their time with friends or family members with respect to the care time.
- Virtual library, which contains a collection of scientific publications on dementia diseases.

Appendix

Comments of carers and interviews with professionals – samples

02--03--2013

Added 392 days ago by: krystyna0560

My mother does not understand what soap and water is used for. She is afraid of baths. I have to force her to wash her hands or go in the bathtub, or even worse, undress her to go in the bath. A gentle tone of voice and asking doesn't help. I think that every patient reacts differently.

Added 377 days ago by: krystyna0560

Mum likes dancing and she sometimes dances on her own, but it doesn't help. I've tried different options.

Nothing helps. As soon as I want to undress her she begins to cry, she beats me, spits, or twists my fingers. She has more strength than me. This happens every day. I know that it is awful for my mum, but I have to wash her because she takes off her diaper and she is covered in urine or faeces. She has a habit that when she needs to pee, she has to remove the diaper. And this is a great problem because she makes everything dirty and I wash it constantly and change the covers.

Added 377 days ago by: Barbara_psycholog

Krystyna, I understand the importance of this issue. I'm wondering and trying to recall suggestions of the support group that I run. One of the group members coped with this problem by employing a nurse to wash the patient and surprisingly it helped.

Sometimes our patients react differently to new people. They display too much emotion in our presence. Please consider this suggestion..... It is possible to receive such specialised care from the National Health Fund, when the patient has been diagnosed with a severe disability. If you have any questions, I am happy to help.

Added 376 days ago by: krystyna0560

Thank you very much for your suggestion. I just do not know whom should I contact to receive information about it. There are neither support groups nor any institutions interested in Alzheimer's patients in our town who would give advice to carers on how to best care for the patients. In a clinic, I have to wait in a queue for a doctor to get a prescription for drugs. It used to be that this could be done via a telephone and you could collect it in your free time.

Added 4 days ago by: maagdalenaa_1978

In my case, it was my patience and my mum's favourite music that helped.

Added 459 days ago by: jolaw

This is probably the most difficult task: to convince father to have a bath. He repeatedly leaves the bathroom, even naked.

Added 440 days ago by: maria

When he is still capable of understanding the order to have a bath, it is a good and pleasant thing, but what about when he is asked to pick his leg up/to leave the bathtub and he does not respond or understand? Then it can only be worse because the carer and the patient are angry, and there are other people needed to take him out of the bathtub when he is wet and confused.

02---03---2013 <http://www.lifepedia.pl/pytanie/36/cwiczenia---aktywizujace---pamiec---osob---otepialych>

Added 444 days ago by:

tanaska

I am shocked that a doctor diagnosed the patient when she was present!!!

Our mother had a neighbour who was diagnosed with Alzheimer's at the age of 62 and she died fairly quickly. Mum remembers this well and often asks with fear if her illness is not the same thing 'that killed Hania'. Of course we deny and explain that it just old age. It is better to adjust the bathroom and replace the shower. I live with my mother by myself so it is very difficult for me to get out even for a moment.

<http://www.lifepedia.pl/pytanie/142/obalamy---mity---na---temat---alzheimer---3---najlepszym---opiekunem---jest---osoba---bliska>

Is a close relative the best caregiver for a sick person? Maybe But is it always true?

MYTH: THE BEST PERSON TO CARE FOR A PATIENT IS A CLOSE
RELATIVE

Added 113 days ago by:

teresa

Teresa--I started giving my husband one pill of 25/hydroxyzinunVP for all his delusions during the night, but I can't see it helping. I'm afraid to give him more without a doctor's consultation. I see a specialist neurologist once a year and when it comes to a general practitioner, they are not interested in such a patient. I only hear that I have to prepare for the worst. I'm already depressed when I look at all the effects of delusions: eating, washing, etc. Why is it so difficult to get advice on this disease in our country? Regards

Added 109 days ago by:

jolaw

I have no idea, my dear, how to properly adjust a drug to the patient by visiting a doctor once a year?? Nor do I know whether a consultation with a neurologist will be sufficient. Maybe it would be better to look for a psychiatrist specializing in the treatment of Alzheimer's? I'm not a doctor, so I cannot give advice. My dad has been sick for a number of years, and I saw that mum cannot cope with it and she sometimes makes completely wrong decisions. I've been trying to look for information, help-- It is worth looking for a local Alzheimer's Association or ask a doctor employed by the National Health Fund. We initially drove to another town to take part in ninety-minute support group meetings for caregivers and the patient was with other patients in the classroom with a therapist at the same time. Those meetings took place once every two weeks. Well, we did not always succeed in going ... But still, we and our sick dad

benefited very much :)) After some time, we organized a similar group in our town, in Wejherowo, and we meet regularly every week. Please do not give up! Take care :))

Added 10 days ago by: maagdalenaa_1978

If you ask me, Pernazinum shouldn't be used to calm people with dementia. It is harmful to the body in the long run.

Added 10 days ago by: jolaw

Please send me more information. I have no knowledge on the subject, but my father takes it daily, and if I remember rightly Promazinum 100 in the morning and 200 in the evening.

Is it the same? Pernazinum / Promazinum -- ??

<http://www.lifepedia.pl/pytanie/22/czy---oddanie---chorego---do---domu---opieki---jest---koniecznoscia>

Added 118 days ago by: Teresa

I've been looking after my ill husband since 2009 and I'm on the verge of not being able to cope. I don't know what he will come up with during the day or at night, and I don't know what to do. My husband became ill when he was 63 years old.

Added 118 days ago by: nisaba

Teresa, I've been waiting for a free place in a nursing home for my mum. It is a very, very difficult decision. I'm trying to persuade myself that I'm doing it because I love her (you know what I mean), and I also love my family and myself. I understood that Alzheimer's is primarily a disease of the carer and their family and then it is the patient's disease. The awareness that she wouldn't want me to be so tired, distressed, irritable and uncared for because of her (as I am now) helped me to make the decision to put her into care in a nursing home. I am faced by acceptance but also a lack of it. It is hurtful that those who should help the most condemn me either openly or by their behaviour towards me. Remember, no one who has not taken care of a patient with Alzheimer's, even if they have a 'bookish' knowledge, don't know what they are saying and they instruct, or even,

God forbid, condemn us!!! My mummy is 83 years old and she has been ill for 5 years. I've been looking after her intensively for 2 years and 24 hours/day since May of this year. I have a family (husband, son and I) and we are all exhausted. We work+son studies+ the ill mum/grandma= a tired home turned upside down. Now, after an almost 2 month stay in hospital, she takes drugs, which 'suit' her, so she is quite stable, but the disease is progressing and we are living on a time bomb.

Added 270 days ago by: nisaba

I love my MUMMY but I don't have strength --night mode, locking the door from the inside, looking as she runs around the flat sweaty and packing her stuff not knowing where she is going, and I run after her, hug her and repeat the mantra 'This is your home mummy, and I am your daughter. You have me to feel safe'. I am strong -- I know this because of the life situations I've been through, but I can't cope with my mummy's dementia.

Added 458 days ago by: Joannap

Putting the patient into care is a veeeeery difficult decision for the family. I was both lucky and unlucky because my mum died at home, so the whole period 2005--2009 I was at home with her. But, it does not say much good about me, quite the opposite -- the tiredness was extreme (both physical and mental). When the carer and the family make the decision, you have to face the situation and think of the consequences. People often forget that the caregiver is also a human being and that they need to rest too, even for a moment change the environment to recharge their batteries...., Even carers make decisions about extra care when they are totally exhausted... I was lucky (because it has to be said this way) in this whole situation because it turned out that I'm quite a strong person. Never in my life would I undertake such a difficult task...

<http://www.lifepedia.pl/pytanie/2/lustra---a---osoba---chora---na---alzheimera>

Mirrors and the person with Alzheimer's

Added 463 days ago by: Robert

My mum has been covering all the mirrors at home for some time. What is the cause of it?

Added 459 days ago by: jolaw

My dad sees some grandfather in the mirror -- an elderly man:) He greets him, strikes up a conversation. I usually notice that it is a very nice, smiling gentleman. Dad comments -- fortunately! I usually take off the mirror for bathing and dad is then calmer and less embarrassed.

Added 459 days ago by: wiesiek

Great idea. I'm wondering whether what you're saying, that it is 'a very nice, smiling gentleman' affects your dad positively...

Added 401 days ago by: jolaw

Yes, I think that my remark confirms him what he thinks and he feels safe. I see more and more clearly that the sense of security is the basis of the patient's better mood. Therefore, even the nicest company of a stranger seen in the mirror is not advisable while undressing for bathing - it's obvious. My dad is a very cheerful person, but lately he has been an aggressive patient. I know he's fighting. I could not stand it when he was called a 'woman beater' ...!

Alzheimer's – carers' opinions

<http://www.forumneurologiczne.pl/forum/vt,0,407,24692,160,demencja-starcza-alzheimer-bezradnosc-rodziny>

- 1) My father is 67 years old and his memory has been getting worse and worse for 3-4 years. I don't even know where to begin. Father is very stubborn and he sees me, his son, as the worst enemy. He suspects that I steal from him. We run a private company and for 4 years he has not done anything but just taken money. He blames me for all the failures that he causes, which is nonsense. He confuses dates, he isn't able to tell what day, month or year it is. Sometimes he asks whether my uncle will visit us (he died 6 years ago). Father doesn't want to hear about an appointment with a doctor. Three months ago I managed to go to the

hospital with him and refer him to a neurologist. After the visit, the neurologist wanted father to stay in hospital for a three-day observation and have a brain tomography with contrast but father discharged himself from hospital of his own volition and the neurologist could not clearly determine the disease. Anyway, when my father is at a doctor's, etc. he instantly becomes lively and lies that everything is ok, and that he only has a pain in his knee (he also has problems with his legs; overweight). He shouldn't drive but he does. On Sunday he drove in a zigzag and crashed into a tree. He damaged the car a bit, but he trivialises it as if nothing had happened... I once didn't let him drive and he called the police, although he had problems with dialling the number... I don't know what I should do, where to look for help. Father doesn't want treatment at all. He claims that I want to convince him that he has a disease. Believe me, I really don't do anything like that. I can see what's happening to him... This hopelessness is killing me.

#####

- 2) Hello! It is important that you're writing about your loved ones and you worry about their condition and helplessness because you'd like to help them. You can't cope with your emotions because it's difficult. I worked in home palliative care as a psychotherapist for 8 years. In January I took early retirement to look after my 87-year old dad. Alzheimer lives with us, but he wasn't a welcome guest. Today he didn't want to tell me what he wanted apart from turning off the light, and he couldn't say anything. I sat near the bed and cried. Knowledge about the disease is important for family members. It's important to accept the condition of your loved one, because it will be easier to look after them. The disease is incurable and in each case there is a different course and pace of changes. There are better and worse days. Weather also has an influence on the behaviour on a given day. One has to first accept this condition themselves. You have to realise that it is neither your, nor the patient's fault. Do not try to explain rationally to the patient that they are not right. It causes more aggression because the patient is able to analyse events, but their logic is different. Aggression causes aggression, especially in these diseases. Remember your loved ones as people they used to be before the disease and bow in front of them in humility no matter what. Hug them to calm them and you will have more peace and satisfaction that they are still with

you. It's difficult at the beginning. Perceive your life experiences differently- you are candidates for aging in the same way. Unfortunately there is such a genetic risk. So act towards the patients as you would like people to care for you in the future. Accept their behaviour and they will adjust better to a nice atmosphere. Don't rush them, don't talk to other people in their company as if they weren't there. This disease affects patient's ability to remember what was said about them. They are not mean and aggressive because they want to be. They don't know about it fully and aggression is just a way of protection in situations when they can't cope. My dad also destroyed diapers and didn't care about personal cleanliness when he was looked after by my brother and mum. My brother has had a mentally disabled daughter for 28 years and his wife died 7 years ago. They were all tired and they shouldn't be blamed for it. Burnout syndrome is normal in carers and they shouldn't blame themselves or have remorse after anger. This is your right. It's better to concentrate on how to solve problems which are the most troublesome and it will become easier. E.g. I make my dad put on pants with legs longer than the diaper and warm trousers, and this makes access to destroying diapers more difficult. In such a way, I try to seek ways to make the care easier. Someone wrote that their father didn't want to realise that they are ill. I have a different problem. I can't convince either my mum or my brother that dad is not mean and malicious, etc. but he is ill. And I don't feel like explaining it to you. I've chosen earlier retirement, although I loved my job, in order to take dad to my home, although I live by myself. Greetings to all and I am sending a smile for every day. Barbara

#####

Hello . I'm Teresa and I'm looking after my mother with senile dementia and Alzheimer's. She is 83 years old. A month ago she fell down and broke her hip. She had an operation, which she coped with very well given her age. However, I have a very serious problem. She is confined to her bed and she should go to the toilet in diapers, but she doesn't. I've settled all the paperwork, I bought and brought them, and it turned out that that it was all for nothing, because she is persistent at taking them off. When she was in hospital, she did the same thing. In order to prevent this, she had her hands tied to her bed. And what should I do about it? She constantly pisses herself and sh...ts the bed and I'm hopeless.

That's why I'm writing: If anyone has a similar problem and knows how to deal with it, please give me some advice.

jagodateresa@gmail.com

#####

- 1) My mum is going to be 93. Problems with her memory started a long time ago. I don't remember how long she's been taking Lucetam for (a drug for brain oxygenation). She's been on Wicebrol for 3 years, and this drug also improves the efficiency of the brain. In December last year my mum started having the same symptoms as the ones described by you. In January I asked a psychiatrist to refer my mother and me (she wouldn't go by herself) to a psychiatric hospital in Frombork. We were there for 2 weeks. Mum couldn't stand it for longer and my nerves had had enough. I thought I would be there among people. Unfortunately she didn't leave me for a while. I talked a lot with her doctor. This stay, however, benefited her a lot. Mum took Tramal apart from other medicines, and this is a medicine with a narcotic. It is a painkiller. She took it for a long time, I don't remember for how many years. The doctor took her off the drug in the hospital and explained to me that this drug could be taken just for a short time because it stops working as a painkiller and causes headaches, dizziness and even hallucinations. After mum had been off the drug, her condition gradually improved. At the moment, she is calm. Her memory might cause problems but she recognises everyone. My only issue is the slavery. Similarly to other families, the care is a responsibility of just one person. Lack of contact with people drives me crazy sometimes but I'm happy that other problems have finished. At the moment mum even helps me with household chores as much as she can because she had a stroke and her hand has reduced function. The administration of larger amounts of sedatives causes a deterioration in her condition. At the moment I just give her Estazolam to sleep.

#####

5) hello

I'm looking after my aunt who has Alzheimer's disease. My aunt is 55 years old and she feels worse and worse every day. She's recently had to wear diapers at night. There's practically no contact with her. She walks constantly and says something , or rather makes an absurd buzzing sound. From time to time (roughly every other day/night) she diversifies our lives with an inhuman howl all night and day or longer. The only advantage is that she is not aggressive... not yet. Oh, I can't even sit down for more than 5 seconds... she walks constantly. When we want to help her sit on the toilet or (un)dress, she screams extremely loudly as if we were flaying her. We have problems with feeding her, because she can't open her mouth. Feeding consists of pouring soup into her mouth (while her teeth are clenched). Do you have any ideas on how best to feed her??

#####

6) Hello. My grandmother is suffering from Alzheimer's. I do not want anyone to go through something like this. Today we had to call an ambulance because she had an epileptic fit. Something horrible. The worst thing is that it is a hereditary disease. It's hard to look at a person who was always close to you and now suddenly stops reacting. Grandma is 73 years old and it started 5 years ago. First it was visits to the neurologist and later a psychiatric hospital (she was diagnosed with depression). Now the doctor recommends putting grandma into care 😞. What person with a heart would do it to a loved one 😞 ? What could I say? Everyone who writes here knows this disease very well. I wish you all a lot of patience, which I lacked at the beginning and now I regret it because I would give everything just to talk to grandma normally even just once. Greetings.

#####

7) I'm 40 years old and I also deal with an ill grandmother (84 years old). I'm also mentally exhausted. Grandma needs 24/7 care, she also has Alzheimer's. She wakes up at night not knowing what's going on, she dresses and wants to go out. He says that someone is in her

room (in the closet exactly). She tries to shoo the 'people' out from the turned off TV. She does not want to eat. I was left alone with this problem and I do not know what to do next. I had to give up work to take care of her. Grandma has daughters who don't care about her (they neither call nor visit her). I personally think that they should respect their mother but what can I do... such is life.

<http://commed.pl/alzheimer-vt64796.html>

1) Hello. I've been living with my mother-in-law, who has this disease, for 2 years and it's been getting worse and worse. I'm afraid that if I have children, she will unintentionally hurt them. Now she is vulgar and aggressive towards me and my husband. We have enough of it sometimes. We go to the doctor with mother-in-law, but we lack the support to know how to deal with such a person, even at home so that it was not life threatening. Please give me some advice. We live near Jarocin. Who can we turn to?

#####

2) I have a very similar situation in my family. My great grandmother lives with my parents (they care for her) due to the fact that her daughters no longer care. And there are tragic-comic situations there, such as hiding everything, talking with people in pictures, fear of films on TV with a lot of action... 'because they will kill us' or a fashion show .. like dressing up in all the things from the closet. Whether the person with Alzheimer's disease is aggressive or not... depends purely on their previous character features .. which can activate during the disease. I do not know the mentality of your mother in law...but in spite of their illness and character .. such people show sensitivity to small children. I'll give you my example. My great grandmother is also aggressive, e.g. in relation to my mother .. when she asks her to get dressed .. She becomes hysterical and aggressive, but when a young child comes to visit us, she keeps an eye on him for fear of his safety. But you would have to consult a psychiatrist or psychologist for more precise advice. They will have a broader perspective on this matter. I wish you the strength to persevere with

the care because I know how hard it is. P.S : There are various financial aid packages for those taking care of people who need it. If you want I can write you a PM about it.

<http://www.nerwica.com/alzheimer-t7305.html>

1) Everything is right! EVERYTHING!

For 8 bloody long years I took care of a person with this disease. 24 hours a day, 7 days a week. All my ***** adult life! One reference or similar situation now causes the memories of this hard work to come for back a few days. I wake up to every creak, this comes back in my dreams (I can dream this incredible stench of the ill), I run away from old people, I can scream at everyone about anything! I know I'll shoot myself in the head when I'm diagnosed with this disease, but at the same time I'll do everything to get this diagnosis as soon as possible. I'd never think this is called... And this is all exacerbated by the ostracism! Has anyone else been through this? Alzheimer's howls. He howls unbelievably: on average twice a week our neighbours (suddenly willing to help!) reported us to the police because we were murdering our old lady. Some things they said: God has punished you! You show too little understanding! There is a freak in this house! You are paying off your debt! This is an illness! And what will happen when you become ill! Because it's your duty! You should do what she wants! You owe her that!

#####

2) Hello!

I think I feel the same! I've been 'pretending' to be a carer since 2005 and since 6.05.2009 my mum has been confined to bed. I'm still coping somehow, I'm already a wreck and I'm ready for the loony bin. It scares me that I cannot function normally and now it is a real prison, because I don't even leave home (only to walk the dog). I write a blog <http://alzheimeregzaminzzycia.blogspot.com/> (invisible in search engines), but it doesn't help me. I have no patience for healthy, living people. I avoid them like the plague. Greetings. Joanna

#####

3) Although no one has written here for a long time, I'll try it.

I'm looking after my 90 year old grandma who has Alzheimer's and it's not easy because grandma lives in her own world and she doesn't let anyone in. We moved with my husband to Warmia from Silesia in order to look after grandma. My husband started working (He is a lorry driver) and I live by myself with an ill woman, who doesn't recognize me (it's my husband's grandma). We've been living with her for over a year and she still doesn't know who I am. She rarely recognizes my husband, unless her neighbours make sure she does (they really care). She would then believe them, because she believes everything they say. Quite recently grandma went for a walk after she left the door open. She fell down, she hit her face on the frozen ground and ended up with a bump on her head and had a bruise covering half her face. When I met her outside (I was coming back from a shop) and I took her home. I admit I yelled at her. Her neighbour came and asked what the noise was about. I told her what had happened and she left (it was Friday afternoon). On Monday about 10 a.m. someone rang the doorbell and it was a lady from social services (we don't even claim child benefit for 3 children) who informed us that the case would be directed to the police because she has been informed that grandma was beaten, bullied and starved. She said that it's her responsibility to react to such violence. When I asked if Ms..... told her what had happened when she was reporting this violence, the lady asked how I knew she had reported it. The neighbour waited for a day and then entered my flat without knocking and stated that she had nothing to do with that. I'm wondering how she knew that I suspected her. A week's gone and the police still haven't come. What should I do about all this? Should I go to the police or wait patiently?

#####

4) My grandmother is dying from Alzheimer's disease (or senile dementia) ... Currently she is in such a state that there is no reaction from her. She talks nonsense, sometimes screams or calls someone, or cries etc. I have to do everything for her because she can't walk but just lies... Maybe it's good because when she could still walk, she either walked and fell and she had her head stitched a few times or she turned the gas on in the kitchen

but she didn't light it... There always had to be someone at home to look after her. Currently my parents care for her but I'm worried that either mum or me will become ill with this disease. I don't know whether I'll be able to look after my mum in such a situation because I have little patience and I can't stand looking at other people's suffering, especially loved ones. I'm worried about mine and my family's future...

<http://www.alzheimer-opiekuni.pl/forum/index.php>

1)najgo60

Tomek you are asking what we could do for you? But how??? The whole family has turned away from us since the problems with her got worse. My husband and I have been left alone on a battlefield. It's been like this for 6 years. When mum could walk 'more', as I call it, we went everywhere together. We took her for long walks in the forest, mountains, seaside and lakes. Unfortunately going on trips ended almost two years ago. We sit at home, she can't walk. Friends don't visit us because they can't bare her calling me names and mocking me. Because it's me, the daughter, who is at the receiving end and I am the worst in the family. Everything I say is wrong, but fortunately she listens to my husband. My sister and brother don't give a fig. And they were her golden children. And us, it's just home, home, home... my psyche is deteriorating, I need at least a few days of freedom and relaxation. Who can I turn to? My sister is deaf to my requests, my brother too. I have two sons, they work, and they have small children and us, the grandparents, can't see them when we want to. The little ones are afraid of the ill great grandma. I inquired about a day care centre for the sick in Katowice. It is too far to drive her 45 kilometres one way every day. My health is deteriorating, my psyche as well. Our doctor suggested looking for a nursing home for mum. Easy to say, where do we start? Where can I take strength from?..... I want to thank my husband who supports me and helps me a lot.

#####

2)Joannap

Unfortunately, I am a living example of a carer who sacrificed themselves because of someone's disease: I will describe (fragments) the last day of my mum's life and what happened later. I know that there are a lot of emotions there, and I don't think I'll be mistaken if I say that all of us go through it every day... I will quote a passage from my article on:

“When you pass an exam on being a human being...”

..... Mummy had a calm, relaxed face, and it was then that I saw that the chest of this small woman, devastated by the disease had stopped moving. I was truly afraid of this moment. Subconsciously I didn't want to think that the disease has taken everything away, and what was left were just some remains... Just like for the entire period of care, she was also alone then. I called the doctor and my mum's son... I remember when the doctor reassured both of us saying: this is a reward from fate, because Basia died at home, in her own bed. She passed away, because she understood that this was her time... To be honest, I couldn't fully understand those words... a reward from fate? What is this supposed to mean? Later I understood what a reward from fate really was when it came to Alzheimer's.

On 15.10.2009 at 10 a.m. my exam in being a human being finished. Just as it started, it also finished so rapidly, without warning...

When I went back home after the funeral, I couldn't really realize that mother is in a better world, free of pain, fear and diseases... The son of my mother went back to work. And I? I was left all alone in an empty house. Then the silence around me made me realize that the exam had finished. At the finishing line there was just a deep wound in the heart, and a lot of experience, which cannot be forgotten... and this overwhelming emptiness. The huge amount of time that I got back was terrifying after the exhausting course of my mum's disease. Only then did I notice how the whole world rushes somewhere ... My first thought: nope, this is no longer for me, I don't want any life marathons... and I literally turned back away from this rushing world. I went back to my little world of books. I thought: the world has managed without one

soul so far, so no one will even notice that I'm just stuck in one place...

At that time it wouldn't even occur to me that that this huge black dog lying at my feet would become my rescue and medicine. Just like in 2008 Lapis (my beloved dog) was the golden recipe for mum's laughter, he also stood firmly on my side and

almost forcefully dragged me out of home. At first they were just short walks, but later I spent whole days outside with him and we came back home just to eat... The dog has helped more than a few therapies: I started leaving my four walls, and I spoke to someone from time to time... It was then, that my problems with... conversations. Theoretically it wasn't a big thing, however... I hadn't really noticed it.. After six months removed from my mother's death I thought that I was about time I looked for a job. I went to the job interview and I literally flew to see them as if I had wings. Unfortunately, the interview was a failure. It turned out during the interview that I have nervous ticks, and to make matters worse I stutter. Such symptoms signify nothing else but strong anxiety. A pretty fine mess. Of course it affected my optimism but I approached it in the following way: I should continue going to job interviews and this will help me assess when I'll be ready to start working without much difficulty. Such a situation is very difficult for a person who previously didn't have problems with conversations and who was talkative. The truth is that I wasted a lot of time because of it... and I locked myself again in my hermetic world. I came back to the carers' forum because during a 'written' conversation no one sees and hears how I behave... Then I started realising that the forum, which I used to look after so much so that it didn't stop, now lives and breathes fully on its own. The members can speak to each other and don't treat the subject of Alzheimer's as taboo. It is an enormous success of all the people who contribute, and I just left a little building block there. My and other people's efforts have exceeded our expectations. Carers have their own place on the Internet. After all this, it is a huge success. The time when I was looking after my mum was not only full of experiences which I will not be able to forget about easily but I use those experiences when carers write to me. I finally stopped worrying about ticks and stuttering. I finally started feeling an indescribable fun because of the possibility to chat with others face to face. I know that anxiety won't disappear like that and that I will continue to have ticks for a long time, but this is no longer important... It is important that just like I used to believe that I would fight Alzheimer's, I started believing that the world needs every living soul.

No one asked me whether I want or am able to take care of such a seriously ill person. No one has said thank you. It doesn't matter. The most important thing is that it is me who turned out to be a 100% human being.

I'm telling the adventure with Alzheimer's once again, but I'm doing it for those of us who are wondering what they should do when they are left alone and there is no one who would say:

You're exam has finished, it's time for normal life now. You're dragging your luggage that you don't really want to carry, but it means that you're a human being.

In my case (or should I say my mum's) it was her closest family: children (adult, unfortunately including "Grzegorz"), grandchildren (also adult people) understood the problem only in the last year of her life. Perhaps that's probably why it all affected me so badly and the only way to unwind (of course I couldn't even go for a walk..) was to write.. First, I wrote just for myself, then, I think in 2008 I got a laptop and then I browsed the Internet. I was terrified when I discovered that there are virtually no practical tips... After all, the disease has existed for a very long time..... Unfortunately everything piled up ... and I also approached the problem differently..., nerves, tiredness etc. Getting to the point, damn hopelessness. I wrote on the blog and forum everything I had in my notebook, and then there was a book. Unfortunately there are plenty of emotions and even now there are places in my diary which I try to avoid, because there's lots of it.. at once. I'm really trying to work out how I managed to involve myself in it so much (I'm not and I wasn't even her daughter-in-law), and then I firmly stood by her side I've been having therapy for some time and I'm probably the happiest person in the world 😊. It is because I'm slowly getting rid of my fears (I have a few), the worst symptoms of anxiety are gone (now I stutter only if something really bad happens or when I'm saying something and not controlling my emotions), fear, shame, regret, and pain are gone forever and that's why I'm such a happy person. I behave and (probably) look like a kid again, because I'm probably slowly recovering the lost years... 😊

I know I'm at the beginning of the road to recovery, but for me it's a milestone... 😊

Everything exhausts me physically but mentally I feel like a 20-year old and not a 40-year old...

I still have this incredible weakness for carers and the topic of Alzh. I admit that I treat this topic as ‘information needed yesterday and not today’, but I’m happy about the possibility of writing about the disease... seen through carer’s eyes...

#####

Iwona

I've been by myself with my aunt's Alzheimer for 2 years, and my mum is just in the early stages. I have a sister, but it's as if I didn't. The same with 'grandchildren'. My sister moved out of Warsaw to the village and she has millions of reasons why she can't look after mum. She doesn't visit my aunt. She's been there just once for just 10 minutes in 2 years. It was a year ago. She drives past the nursing home at least once a week.

When it comes to me, I've always liked being by myself. I don't think I'd be bored if I was suddenly without my mum and aunt and all those chores.

I recently got some cats. And until recently we always had dogs. They passed away to other side after long years of life. I'm worried that mum might let them out, because they are house-bound cats. Such cats, when they cross the threshold usually disappear forever. Of course, now I lock my mum when I go out and there is little possibility that they will be let out. My windows are only partially secured, because not all of them can be opened, as there's no need for it.

I'm at a loss in this situation. Putting mum into care at this moment would be inhumane. She still understands too many things. These are the beginnings. It is the worst in the morning. She is completely lost, nervous, she can't remember anything and she asks about the same things every 3-4 minutes.

It is better in the late afternoon or in the evening, however, she can't sleep in the evening. I play a 'question and answer' game with her. She can't remember what her sister's name is, where she lived, what her husband's name was, and which street they lived at. She doesn't remember the names of our dogs, where my sister lives and many other things. She realises this and she is really irritated. The complete lack of emotions is the worst. Someone could shoot me dead when she was looking and she would not react. You describe here the stories of your close family, but it is usually two or three people that take care of them. I am by myself, and there are two people. I don't know how many people deal with a double problem. I presume not many.

I don't know yet how and if I'll be able to organize myself.

#####

WNUCZKA

Iwonka, I think I can imagine what you feel... I was in such a situation for a month when I practically looked after grandma, and my dad was in hospital. I despaired for a long time about why I was in such a situation. At about 7.30 I went to the hospital to feed my father. My husband, who managed to swing it with his colleagues so that he could start work at 9.00, stayed with my grandma. I had to be back home at 8.30. I was by myself with grandma until 6.15-6.30. My husband came back and I went out to visit dad. However, there were days when I didn't have energy and was exhausted, usually mentally and I didn't go. Of course, I was usually in hospital when my dad was either asleep or very tired, and it was very difficult to catch a doctor in the morning and there was only a doctor on call in the evening. I constantly had remorse that I either didn't have time for dad or I wasn't taking proper care of grandma (mainly due to high sugar levels). Or I thought why it must have happened to me and why my brother didn't help me as it was also his responsibility, or that there are things that I am not able to do, or that I sacrifice my life and my family etc. Of course you can always talk to your sister. Maybe she doesn't realise the difficulties you're facing? Although to be honest I think that it should be her who should take an interest in your mum. When it comes to your aunt, does she have children (maybe you already wrote about it somewhere and I missed it)? It's been already said that your aunt is not going to get hurt in the nursing home. I know it's difficult to talk to some sense into yourself, I have problems with it as well, but you really can't control everything. You have to reject the guilt, because you can become ill from this! In my dad's ward there's a man with whose family doctors have no contact with at all! You're doing so much by looking after your mum and aunt, and you deserve to THINK WELL ABOUT YOURSELF and have no remorse!

#####

Iga

Hello everyone, my name's Iga (42 years old). I've been dealing with my mum's (72 years old) disease for 6 years.

I've registered on the website, because sometimes I would like to talk to someone who understands the issue. During all those years I, first of all, learnt that anyone who hasn't looked after a person with Alzheimer's disease on a daily basis, has an idea what it

is and with what us carers have to go through. I don't mean just washing, feeding, giving medicine etc. (that's the easiest), but I mean second guessing the patients' thoughts, predicting their reaction, behaviour in a given situation. For me personally it is awful when I have to e.g. organise the life of my family (my husband, children 16 and 10 years old and I) 'around' the care for my mother because always someone has to be at home. I have to point out that I have a wonderful carer for my mum (a lady who is 72 years old). For me she is an Angel on earth. She helps me as much as she can, but I don't want to 'exploit' her because of her age and health. However, I would never change her for anyone else. Mum adores her. I also have a wonderful son, who stayed by himself with his grandma for 4 days and he looked after her with the carer's help. Thanks to that I could go with my husband and younger son for a long weekend. I'm also lucky and unlucky at the same time that mum is very calm and dependable. When you sit her in one place, she won't move until you tell her to. It's all ok, but it makes me sad that I will never be able to talk to her normally and I won't explain a lot of things to her, and that we will never fix our relationship from before the disease. At the onset of the disease I wasn't good to her, I rebelled. It took me 6 years to understand her during her disease. But it was not without anti-depressants and psychiatric help. It's OK at the moment but I have moments of doubt sometimes. I thought about putting her into care to a nursing home. I settled everything that was necessary, and I.....couldn't. After all, somewhere there, with some sense she knows she is at her place and in such and such environment, and she is safe. I've decided that as long as she is so calm and executes commands with my help, barely walks but still (she doesn't go out, she can't walk down the stairs), then I have to cope with it.

Phew, I've written so much. It's to relieve myself. Some other thoughts will probably arise, but I don't want to bore you.

#####

Anhedonia

Today I registered and introduced myself. Now, I'm opening a new thread because Tomek encouraged me. Each of us writes their story in their own way, how they can and how they feel it. I have a 'problem' with myself. My mum passed away a few months ago. I am on the one side and she is on the other side. It's just that our sides don't link. For many years I thought that looking after an elderly person who suffers in many different ways (including Alzheimer's dementia) is a task beyond one person's abilities. And now? I can constantly see her, her fear and horror, and her attempts to run away from home, which she didn't recognize. Maybe now I could have done it better, differently, and more patiently? Perhaps not, but at the same time I was left with such experiences and so much knowledge for nothing? I tried to do something good out of it and write it down as easily as I could. I created a blog for carers of: the elderly, the disabled, the incompetent and I attached my FB page address. This is not a diary, but an attempt to reflect from the point of view of a former carer. I never got real help or support, but just people's assessment. I felt watched constantly. But maybe someone else will want and know how to use it? The entire project for people with a soul (because carers have a great, wonderful soul) was established in April 2012, so it's relatively new. I'm giving you the link <http://ludziezdusza.blogspot.com/>. Greetings to everyone.

#####

Sara

Before I didn't have the courage to write anything myself but now I think I should as a warning to those who are in the early stages. Look for help wherever you can. Don't be by yourself with it. I agreed /I don't know when and how/ for everything to be put on my shoulders and I didn't understand in time that I couldn't cope. I went through hell, I believed that I was evil and heartless because I did not know how to handle it, I failed and I lost patience and control. I simply couldn't cope. I wanted to especially thank Joannap and Tomek. Their texts allowed me to see the light. I tried to leave the closed circle. I started fighting for myself, and it was just a pity it was so late. I understood that what was happening to me were the symptoms of burnout and depression. Maybe it would have been better if it had been a mother who loved me and brought me up and not,

as someone has written here, a mother-in-law who had never accepted me. Abora, I know what you're writing about. It's difficult to forget about loads of negative emotions, which adds to the frustration and regret. And now when it's behind me, I have a great sense of guilt.

#####

Arleta39

I was angry all that time at mum that she became ill. I don't know why. It wasn't her fault and I, as a nurse, should have dealt with my emotions better. Mother died 3 months ago and I should finally have rested but I think I have a some kind of carer's syndrome, because I couldn't even watch a TV programme about people with Alzheimer's, because brought a lump to my throat. If mum hadn't died, I would have probably had to go to a psychologist. I was angry with my father and brothers that they left me with all that. I also want to add that I gave birth to my daughter 1.5 years ago and it was very difficult. I have 2 older children and my husband goes abroad for work so I was by myself. I asked myself what would happen if I became ill and I know

#####

LUCIA

Hello. I've read all the posts and.... I'm terrified of what I'll have to deal with. At the same time, it's great to find a place with people who have the same problem. People who have been through this problem. I'm looking after my 91-year old mom, a woman who has never been warm to me, and has never given me love or positive feelings. She only had expectations that I tried to live up to. All her feelings, which she had, she gave her youngest son, who was an alcoholic, but she claimed she had never seen him drunk. He drank himself to death and I was to blame of course because as an 'older daughter I should have saved him'.

I can't write. I can't gather my thoughts, but maybe it will go.....? "What doesn't kill you makes you stronger". Maybe it won't kill me, but I wouldn't want my children to go through what I've been through.

#####

joannap

Hello All,

There are a lot of people here who know me (at least through writing. I met a few people in person...). I finished my task a long time ago (that is 2009). For me this subject finished in a room where I had my therapy... (because of e.g. fears, as being locked in 4 walls caused awful fears- nasty afflictions...)

I've read everything that you've written on this topic:

I am a practical person by nature, that is I take it without anaesthesia, without unnecessary beating around the bush...

After that I had awful problems... How should I live now and why on earth I should fight for the rest of my years which I would have to spend in this world- this is what I thought straight after...

It is obvious that everyone has to go through a phase of crying and running away from life in moments of breakdown (for some people it takes a moment and for some others it takes years...). I don't cry for myself for a long time... At some point I reached a 'wall' and I could no longer be stuck there... This is what I did, or maybe that happened that made me start doing something with myself:

It was sheer coincidence that I spoke to a carer (he's still a carer...). He devoted his time to me... we spoke for a few hours... just like that... he let me talk... I respect him a lot and I am so grateful he listened to me talking about things that not everyone could hear... Thanks to this conversation I understood: "Andzia, it's about time to look after yourself. You won't help anyone effectively if you need help..."

The problem was that:

1. I knew that drugs wouldn't help, because it would be like 'I'd go and drink off my problems'-I'd forget for a moment. It is a sure way to addiction. When someone starts taking tablets, then they will take them for the rest of their lives.

2. Looking for a good therapist is like trying to find a needle in a haystack.. You should know that not every therapist is suitable to listen to such experiences... like death... or let alone death in regular instalments...

A long time ago... when I was in a very tight corner, I was forced to go to the Woman's Rights Centre... without drugs... I thought there were some experts that would tell you what to do if need be and would tell me where to go in the most difficult situation. So I went there... I survived care without anaesthesia and I went through therapy without anaesthesia. It was a long process and at the beginning I stumbled over my own limitations every now and then... After I'd made progress in one matter, I retreated by light years in another... But in the moments of doubt I would sit and write ... Why? In order to spit out everything that causes stress.. grief, pain... Just as I used to write about my mum, I started writing about myself... You know, it's as if one person is burdened with too much and there is no way to escape.. You just withdraw and just go crazy because you can't see the light at the end of the tunnel.... The concept of losing a loved one itself is a huge trauma ... let alone when you look at someone's death and you can't help in any way... It's not just about Alzheimer's... there is a whole bunch of other carers for people with fatal diseases here... A common feature of all of us is, unfortunately, the experience of it all...., and a huge mental pain.

You can soothe physical pain, but you can't do it with mental pain... Only those who have experienced these kind of nightmares at least once can understand it... It was only last year that I rose from my knees... now I can talk to people, I don't have symptoms of neurosis, and I got rid of my fears ...

Now the state in which I am is like being a freshman- excitement, and joy, but also some anxiety, because I discover everything anew. What was "accidentally" found during the therapy was that apart from the experience of being a carer, I also have other "issus" hidden in the deepest recesses of my soul ... For me therapy meant learning life anew... I'm the same person but I'm so different inside... In theory everything looks good and gives a boost of optimism... but I have to keep the theoretical guidelines in mind all the time.... because I really do not want to go back to having nightmares... The most difficult thing about therapy is to start talking... outloud... about what you feel...,

and struggle with your limits is the next level of difficulties. But the hardest thing of all is to FORGIVE YOURSELF for moments of weaknesses...COME TO TERMS WITH YOURSELF.... AND GIVE YOURSELF A CHANCE TO HAVE A NORMAL LIFE! It affected me so much, that is, it affected my soul... Now that huge wound I had has healed up. I ended up with a huge respect for life and other people, and you can still read my face like from an open book. I am not afraid of other people. I know a person is not a glass and you can't know what they have inside. However, now I remember about the margin of safety... I know that what I wrote to you might not be very useful, because finding a good therapist is not an easy job... I know that I once had a bit of luck because I found a few people on my way, without whom I would be stuck in one place... Fortune just smiled on me 😊

At the beginning of your recovery it helps a lot to sit down and start writing. Writing down everything you have in your soul... helps you to look at everything from a different perspective... I won't reinvent the wheel when I say: talk, talk... I know that many of you don't even have a person to talk to, but here on the forum there's always someone who will willingly talk to you. If not on the forum then via a PM.

CARERS HAVE BEEN AND WILL BE PEOPLE GREATLY VALUABLE BECAUSE OF EMPATHY AND THEIR SOUL. THAT'S WHY I BEG YOU NOT TO GIVE UP. FIGHT FOR YOURSELF..... WOUNDS HEAL. YOU CAN LIVE WITH SCARS BUT NOT WITH OPEN WOUNDS. I AM SO GRATEFUL TO EVERYONE FOR BEING WITH ME DURING ALL THOSE DIFFICULT MOMENTS, FOR SHOWING YOUR UNDERSTANDING. I THANK FATE THAT I COULD MEET YOU AND THIS RESTORED MY FAITH. THESE ARE THE TREASURES WORTH LIVING FOR. IT IS YOU, YOUR WONDERFUL SOULS, WHICH ARE UNIQUE AND ONE OF A KIND.

Greetings to all of you,
Asia

#####

Annakoz

I don't want to write negative things but personally I think that Alzheimer's and psychiatric illnesses in general are the most tragic diseases that rob one of one's dignity. Unfortunately, that's what I think and I deeply challenge "God's will" in this respect.

My mom, who is 72, has been diagnosed with Alzheimer's almost two years ago. She lives in Poznan while I'm living in Warsaw for the time being. I visit her on weekends and I manage medications by the phone. We're both single. Mom's getting worse and worse so after thinking over all pros and cons I decided to move back to Poznan. I'm looking for a job in Poznan, ineffectively so far.

Mom's getting crazier and crazier; she's also hyperactive and agitated. She's gullible and careless making friends and is doing silly things. She represses the thought of an illness and is blaming me for all the bad things. Unfortunately I am rather short – tempered, emotional and cannot distance myself. We have never been getting along too well, we're so different. Now it's getting worse and our relations have become rocky.

When I move back to Poznan I don't want to stay at my mom's home but instead I'd like to find some place to live nearby so that I only come round to see her. I'm also thinking about a [paid] female caregiver.

It's too early to let anyone move in – mom thinks she's perfectly all right. She wants to manage her own life and gets angry when she is being "supervised". On the other hand, she's looking for friends and is upset when alone so she has to be supervised.

Give me some tips if you have any idea what to do. Do you happen to know anyone who is patient, cultural, knows the problem well (mom is very picky when it comes to making friends) and is looking for such a job in Poznan.

Cheers, take care.

#####

MMA

Hello, I have just found this forum but haven't been able yet to read what's written here. Someone here may have had a similar problem but I found myself in the role of a

caregiver a few days ago and I feel completely lost in this situation.

I don't even know if everything what's happening to my mom is a symptom of dementia. For the time being I'm trying to convince myself and trust her current psychological symptoms are reversible.

I'll start my story from its end. My mom, 77, has been admitted to a cardiological ward on Jan. 10 because she had symptoms of chronic circulatory insufficiency. Incidentally, she's had the symptoms for a long time now but she hasn't gotten any treatment so far. This is a separate story, just like the description of her days in the hospital; I'll go back to this later on. During my Mom's one – week stay at a hospital I could see that her psychological condition was becoming worse and worse every day. Initially, I was worried by her brain fog and blurred speech. She was difficult to make contact with. This situation lasted for four days and on the fifth day I became horrified. She began to talk nonsense. I even have an impression she was hallucinating and slurred something incomprehensible in her sleep. Naturally, I let the supervising doctor know about it but I didn't get any answer other than the information that she will leave the hospital in a worse health status compared to her health status upon admission to the hospital. My fears came true.

Another problem that emerged in the hospital was her total loss of self –reliance. Mom is physically handicapped (she has advanced osteoporosis). She has recently complained about back pain (that was the main reason why I called for a family doctor. Home visit resulted in her being referred to the hospital but, as I wrote, it was due to her circulatory insufficiency). In the two weeks before her hospital stay my Mom would get up from her bed with my help, despite pain. She would use the toilet on her own and cope with washing herself, despite all the difficulties. What's most important, she would let me know about her needs whenever she needed help. In the hospital she was immobilized right from the start, however. She was inserted a catheter plus diapered. She was immobilized for five days. I forced a specialist doctor to consult my mom. That was it. On the next day I found her sitting by her table. It turned out that a nurse could “mobilize” my Mom even before a specialist doctor's visit. She could also give me some tips on simple exercises to strengthen my mom's muscles. The consultant only confirmed the recommendations that she should be physically active to the best of her

ability and signed a request for a walker. Two days later my mom was discharged from a hospital in the “optimal” status (just a citation from the discharge report).

Currently “optimal” status means that she is still experiencing the above mentioned mental disorders. I hardly manage to make her leave the bed, take medication, eat her food and, above all, drink something. She can still talk sense at moments but we actually cannot communicate with her in a normal way at all. She seems not to understand what we are talking to her although she can talk quite logically sometimes. She’s disoriented but can recognize family and friends. I turn the TV on for her but she’s staring thoughtlessly at the screen. She even stopped reaching for a book (she tried to read on the first day but it was only a reflex). She is trying to use the toilet but at the same time she poops to her diapers.

I have to manage these problems on my own for the moment. I was astonished by the situation and I’m just trying to fix things up and “get things done” myself. “Getting things done” makes it difficult for me to make sure some is always here with my mom. Additionally, although I know I will need a paid caregiver’s help, I still cannot determine the extent of that help because I am still under the illusion that this dramatic situation will come to an end, that it’s going to get better. I’m going to stay at home for one more week (winter holidays). I may take a week off work for caregiving (I have already taken four days) but what am I going to do next. My optimism and the feeling that it’s going to be better result from my “Internet education”. Also, I have been comforted by a hospital nurse, community nurse and some friends of mine. They told me that such psychological symptoms may be a result of a hospital stay and a side effect of treatment (loss of electrolyte equilibrium, dehydration). I have an adrenaline rush; I have been continuously living in stress that is increasing and increasing for three weeks now. I fell exhausted, both physically and mentally, but it’s only the beginning. Also, I’d like to ask some good doctor for a visit but I have no idea where to look for. I hope someone here can give me some advice.

#####

Anhedonia

czarną dziurę. Nie umiemy sami tego powstrzymać, czy chociaż załagodzić na tyle by

I know from my experience with my mom that her physical and mental health status repeatedly deteriorates following a hospital stay. On the one hand, it can save her life but on the other hand, the treatment led to her deterioration (medication change, bed rest and immobilization, forcing her to put on diapers and so many other things). She was alive but she looked as if she came back from another world. She could not recognize her room. We were usually able to make it so she almost restored to her old self before the hospital. It entailed time, patience and improving functional capacity. It may be similar in your case too. Confusion due to changes in the surrounding, medication change or ischemia is frequent in chronically ill elderly people but they may be reversible. Best wishes with all my heart. Anka.

#####

Ewa

Hello, six months ago my Daddy spent a few days in hospital just for a medical exam. I would visit him every day and I could observe an incredible change in his behavior. Although he was not diapered or anything like that, he began to behave in a completely different way than he used to behave while at home. I suppose that the change of the surrounding made him feel somewhat anxious and unsure. His hands were trembling so hard that he could not hold anything. He told us some nonsense stories. We made his hospital stay as short as possible, to what was absolutely necessary. After his return home, it took some time for him to restore to his old self. I don't remember exactly but it took a few days. Now we're driving him to a day care center three times a week. In the beginning, I had to assure him I would go back and pick him up each time. Now he doesn't even ask. He's calm and even glad that he's going to go there but he's also glad when I come to pick him up. I don't know what it's like with other ill people but, as I could observe and sense myself, the feeling of security and the awareness that he's surrounded by his relations who love and respect him are very important for my father. I keep on repeating how much I love him, how important he is to me and how much I owe him. I can see that he finds it pleasant and his mood improves. I think that a hospital stay

may worsen ill person's mental status and I also believe this process can be reversible, czarna dziura. Nie umiemy sobie tego powstrzymać, czy chociaż załagodzić na tyle by Bide your time and hope it's going to be similar in your case. Best wishes.

####

Acuarela

I have already met you here in this forum but I forgot my nick and password so I'm doing it again. My dad has been diagnosed and has been solely under my care since January 2011 (he's 67). His has recently worsened so much that I had to give up my job. Although I formally worked ¼ full time equivalent, I used to work as many hours as full – time workers (as it happens in small towns with poor labor markets) just for peanuts so I don't have any regrets. What I want to say is that after all it's a change, the end of some stage of the disease, an irrecoverable loss of the loved one's previous level of functioning and having to face the unknown – the advanced stages of the disease. If there are any people who had to quit work just as I had to, my question to you is how you managed to cope with these changes psychologically. It's still possible for me to earn some extra money at home so I am not out of work completely but I may lose my colleagues, who used to console me. To add, most of them cared for their parents and grandparents until their death. I'm waiting for your posts. Cheers.

#####

Krystja66

My mommy has had the disease for six years now. After her husband's death, she lived alone. She has always been extremely clean. In the beginning of the disease it was relatively all right. She would tell thought – up stories and talk about me, my children and our neighbors behind our backs. On and on, repeating the same stories again and again. She would brag about her popularity with men after her husband's death, what was not true. These were only her delusions. She was yelling at me that I'm going on holiday and swore at that I'm not conducting myself properly. When I came back she did not let me in and told to me to get lost. She swore terribly, so many terrible f words. I tried to explain that I work all year long and cultivate my allotment garden from early spring until late autumn so I have to reset myself and take two weeks off from my daily

routine but I could not get through to her. She was nervous and could not control her emotions so it was better to get out of her sight. She stopped going to church or doing shopping and gave money to the neighbors for their shopping. She also gave 50zl to the mailperson and something for the grandchildren too. She would give away the money to anyone who came by. I was unaware of the illness and did not pay attention because she would not let me in and I didn't force myself upon her. My daughter would visit her and wanted to talk her into reconciling with me. It took some time before she decided I could visit her and pay the bills. It turned out she did not have a spare penny and there was no money to pay the bills. Ever since that moment I took care of her retirement pension, shopping, bills and I even had another duty. It was horrific. In the morning I would go to my mommy's place, then go to work, then do my mom's shopping, then go home, then the allotment garden, dinner and going to bed. But it's 11 p.m. and the phone is ringing. Please come here. I get dressed, go to her place, and come back home at 1 a.m., a few hours' sleep and then get up again. In the morning, fresh bread everyday or cereal because she likes it a lot. I'm at her place at 7.10 a.m. and am starting work at 8, I come to her place at 11 and go back to work at 1 p.m., then a lunch at 4 p.m., after lunch do the shopping and then go home. I come to her place in the morning and the neighbor says that my mom visited her at 10 and said her daughter would not visit her and she was hungry. Then the neighbor explains that the daughter visited her two hours ago and came up with "I'll get you some food" but my mom didn't want it. She kept visiting another neighbor, tomorrow continued. She kept coming to another neighbor, she would hide everything I brought under the pillow or in the drawer and showed how I starve her, that I'm a wayward daughter and don't care for her. The neighbors would come up to me and my daughter, say that her complaints were the bane of their lives and I was helpless. We would have the dinner together every Sunday, we would swap making the dinner so that we could spend as much time with the mommy as possible but it wasn't any better. My daughter and her husband work while my son goes to school so they do not have too much time but I can always count on her. She would always help with the bathing. I wouldn't be able to do it all by myself because my mom weighs 74 kilos and I weigh 51 kilos. She also didn't want to bathe at all, not for the world. I wanted to take her to my place, no chance, she would not spend here two hours, get her home. When I insisted on her staying at my place she got nervous and was about to beat me up or took her

belongings and went her way. When I was about to leave for holiday I hired a female caregiver, I would ring everyday but when I came back the caregiver said she [my mom] put her through the wringer, she's had enough and quit. I put an ad in a newspaper "a flat to rent plus allowance for caregiving". Some young people with a baby came by, I was glad they would make a family and my mom would not be alone but they didn't care for my mommy, she was so frail that I took her to the hospital. She was treated with drips so I sacked them. So again I wrote to the newspaper, there was one lady who was single, really nice, she even moved in and they would go for walks together. I thought they even started to like each other and I had a short rest but the lady quit too. There was another lady who did not manage to hold out. They were all dog – tired, all four of them. So I made the decision and moved in to my mom's place. I wish I had made this decision much earlier. ...now I can see why my caregivers would run away. I'm going to write what she was doing. She threw the garbage through the window, poured water to anything that came in handy, turned off the refrigerator. She took the glasses, plates and dishes and put them in the living room, she took the food from the refrigerator and the freeze and put it on the table, repeatedly asked about the same thing, watered the flowers everyday so that they rot, poured the tea under the carpet, spit, hid the garbage under the carpet, took the feces from the toilet and put them on the washing machine or washed her hands in the toilet. She would take the wet toilet paper and make paper balls. She dried herself with a towel instead of paper. She would poo, wrap it in a paper tissue and put in on a cupboard behind photographs. She didn't want to bathe, she would run away and get nervous so she yelled and used many F words. She didn't want to go for a walk; she would put different clothes all together, fall down on the floor and lie down. She would wander at night and in the morning and would switch on the lights everywhere. The washing couldn't wait, she would pour out the water and hang it unrinsed wherever or put it in the drawer. She would hide everything in her sight so it was hard to find it. She yelled that we are robbing her, she would eat the box full of sugar, a box of chocolate, sweets, chocolate, everything at once without limitation, a box of cheese, sweet wrappers, banana peels, fruit peels. She would throw the diaper from a window; she would pee on a blanket, a sofa and a chair. She would even pee while standing in the kitchen. She would always repeat that she had no appetite and she was crazy about tidying, true as it was. As much as she liked going to church in her old days she stopped

enjoying it when she got sick. She would open the window and scream for help, that she's hungry. I put a phone number on the door so that the neighbors could call. She would wipe the sink dry so the kitchen towels were always wet. If something was not according to the way she planned it she would always say "I'm moving out", "I'm going to a nursing home" or "I have a pain in my back" and so on. To continue with, after I moved in, it was very difficult in the beginning. I left my home and my allotment garden, my previous life and I started a new stage of my life when I already knew the burden of the illness because I had read two books about it. Back then I didn't have a laptop; the doctor administered the right medication and diapers. I was totally inexperienced but I was fully aware of what I was doing: I became a full – time caregiver. In the beginning her behavior irritated me and got on me nerves but I soon realized I couldn't do anything by getting angry and nervous. I would only worsen our relationship. So I started to treat my mommy not like someone who is sick but like a baby, who is being brought up without stress, surrounded by love and kindness. And because I am a well – organized person I prepared a scheme. An ounce of prevention... What do you do with children? You love them, organize different games, walk them, feed them, dress them nicely, bathe them, change diapers, read books, watch the photographs, dance with them, have fun with them, take them everywhere with you if possible, watch TV and explain a lot to them. I had difficulties doing it because my relationship with my mom had never been too good, she couldn't talk but she would rather fight or yell instead. On my way to church I prayed and asked God for more patience, peace and understanding. Because we all know that's what we need most. On my way to work I would say again and again that I could not get nervous because I didn't know what I was going to see at home. I realized it was up to me how our life with the illness would go on. I noticed that my mommy was watching me, my mood, how I behave. So I always try to smile and be happy, I hug and kiss her to say hello, to say goodbye and to say goodnight. I never yelled when she did one of the things I mentioned before, I only tried to explain and pretended everything was fine. I managed to conquer Alzheimer's. When I moved into my mom's place, all cupboards, the fridge and windows were fastened with a tape. I removed the tape and wrote down notes for her but it didn't help, mommy would tear it away and hide.

So I began to observe her and hired a caregiver for the time I was away at work. But my mommy didn't like it, she was angry, nervous. She would always play some tricks. Sometimes she was happy for us to live together; sometimes she was angry, nervous and wanted me to get out. The caregiver tried to give me some tips. She said I should scare her that I will put her in an old people's home or make her go away if she doesn't stop behaving like this. I didn't like this advice at all. When I moved to my mom's place, I also changed my workplace so now I have only 5 minutes' walk. As a result I began to observe their relationship, what it's like when I'm outside. I could hear yelling and swearing through the door.... So I paid her and kindly said "thank you". I hugged my mommy and talked a lot that we have to cope by ourselves. I don't know how much of it she understood but she nodded her head. I stated to make a plan for myself without a caregiver. And it was the real fantastic bull's eye. I know a mess; dishes in a draining board get on her nerves. Nothing in her sight, dry sink, no crumbs on the floor. And I adapted to this. To add, I cut her hair, did a perm, lightly polished her nails, rubbed the balm after a bath and she was really so happy about it. She repeated how much she loved me, how happy she was to have me and repeated "I love you". Mommy understands when someone is good for her and reciprocates with not doing anything to spite me. She became very gentle, doesn't swear, doesn't get nervous and I'm happy that everything is all right. In the morning I play songs she likes to hum so she gets up with joy, jiggles about and sings, I kiss her and ask her how was her sleep... and mom says it was dry, then we both laugh, I change her diaper, dress her and open the windows for one our, put on her cap and gloves. We do several bows to move the body; we dance a little, then a breakfast, milk soups to which I add ground walnuts, hazelnuts, almonds, pumpkin seeds, sunflower seeds and ground flax – seed. One spoon of it to other soups too. I give her a tablet, she has a nap and I go to work. I leave a sliced apple, some fruit, a box of cheese dessert or some cookies. I come back at 11, and then come the kisses, washing hands; we have a coffee together or some cake and go walking if the weather is fine. Mom has difficulty walking so we're back in one hour; by the way we live on the third floor. We usually undress to the rhythm of music; I make a sandwich and cut it into pieces, a cup of cocoa or milk. Mommy doesn't like tea, I feed her and change her diaper and go to work while mom is having a nap. I come back at four p.m., many hugs, I prepare food and feed her because when she eats on her own she gets dirty, I wash the

dishes, mom goes to the kitchen and checks it out, and then we watch TV. On Sundays we got church and to the cemetery, sometimes to Polanica to have waffles or ice – cream and have a walk. She is really so happy when I take her to a senior citizen’s club. She would often fall so I moved the sofa to the wall and installed handles similar to the ones in the bathroom. I fitted handrails around, got a walker and now I’m in peace. I’m glad that she sleeps at night and uses the toilet on her own, she’s calm and quiet. Mommy understands what I’m saying to her but doesn’t know how to express herself. When I have my meetings or go dancing at the senior citizen’s club, she’s glad and says that I look good, “have fun!” she says. Mommy is 88 years old so when we went to a grandson’s wedding party she had real fun. I wanted to share my story with you because, as we know, our stories are so different but we can draw conclusions from each of them. At least I learned to write a little bit faster and it’s difficult at age 67. I have a problem because my mommy drinks little, no juice, no tea, no water or stewed fruit. She swallows everything dry and has only one little sip. Maybe one of you here has some idea what to do? ☺ When mommy is calm, she has a nap after each meal. She won’t do anything bad. She bends over and it’s like her right arm is limp. She hasn’t fallen down for a long time now and uses her walker. I also fitted handrails in the room, in the hall, in the kitchen and in the bathroom. Regular handrails made of plastic pipes. The doctor comes home, does his check – up exam, the nurse takes blood and urine samples, everything is normal including sugar levels. She has become so gentle after I moved in.

#####

Klikaz18

Hello everyone. I don’t know if it’s the right forum for me but it’s up to the moderators who can remove my posts or you can write that it’s not yet the right time for me to be here with you. I’ll put my story in a nutshell. I’m 19 and come from a little town. I was brought up in a family with an alcoholic father who ruined our family life. We managed to evict him in July 2012. Ever since that moment mom has become forgetful. These were unimportant things in the beginning but later on the problem aggravated. We had to repeat something to her Several times, she would forget the date. Well, it’s a shame to mention it but we thought it was temporary. Mom had a hard life so she had a right to be forgetful. She was admitted to a neurological ward on Jan.7 (she was already referred

here before but all places were taken). In fact, when she was just about to be admitted, czarna dziura. Nie udało mi się tego powstrzymać, czy chociaż załagodzić na tyle by her symptoms disappeared. She spent two days in the ward, after two days she phoned me to say they were signing her out. When I came to the hospital, it turned out it wasn't true. Mom was referred to a psychiatric ward with a diagnosis of partial stupefaction with a depressive syndrome. And here the story begins. My mom has been there for three days, there is no improvement. On the contrary, it's getting worse and worse. She doesn't remember the date at all; today she told us she had been there for two weeks (three days in fact) and so on. I have visited a doctor and it turns out to be the early stage of Alzheimer's disease. I know that I'm the one who has to provide care to my mom because I have always been close to her. I don't know what to think about this disease. I searched the entire Internet and didn't want to learn anything else. Will the persons with this disease have lived for 5 – 12 years from the moment of the diagnosis? I can't imagine that.

Mommy's functioning well yet, she gets by, she is only forgetful.

I decided to sign her out from the hospital on Monday because I don't think they are taking good care of her. I still go to school and I'll see what's going to happen next. I can't imagine she can forget me or my name. Help.

#####

gagatek

Hello, I'm a newcomer here in this forum and don't know how to start. There is one thing I'm sure of: the level of my frustration is at its peak and I have to look for help.

My 76 year – old father has all the symptoms of Alzheimer's: memory problems, he is constantly losing his belongings (keys, wallet, glasses, his documents), is looking for them all the time and accuses everyone at home of theft. He loses orientation in time and space (he can't stop asking for the date or the hour), is becoming negligent about his personal hygiene. He confuses my name and my sister's name. With time he also developed problems with speaking, participating in a conversation and so on. I can give

you an endless list. Any basic daily activity is becoming a great problem. He spends money on various unnecessary things or he puts a deposit but forgets in which bank.

These symptoms have lasted for a few years now but they are increasing and increasing everyday. The worst thing about it is that my father became aggressive. He used to have a difficult, volatile personality but recently he has been lashing out at everyone at home for any reason. We can hear endless attacks and accusations. What's even worse he's about to fight. We live in fear because our mom has had a brain tumor operation and the father started to get her with his fits a few times (a fall can be fatal for her). The father has become unpredictable and just when we leave home we are thinking if anything like violent fight is going to happen.

Lately, it's becoming worse and worse. The father cannot make it to the toilet (he's urinating on the toilet floor –if he's lucky enough to get there). On that day there was one horrible event. He suddenly started to wet himself. He wet his trousers, then took them off and after that began to walk around home. He would urinate every moment. Before going to bed my mom asked him to put on a diaper. It made him so angry that he pushed her with all his power (luckily she fell on the sofa and it ended with a little bruise).

We cannot dissuade him from driving and going to work. Despite the fact that he has no scheduled activities on that day, he goes to work and we are trembling: driving code does not exist for him at all; he drives at red lights, does not look at street signs and gets lost. The heart of the matter is the fact that he doesn't have the diagnosis. We have visited our GP several times and asked him to refer him to a diagnostic examination. Still, despite our relations we didn't receive a referral. We only heard his mood swings could be associated with his long – term diabetes. A visit at a neurologist's was ineffective too. We don't know what we should do or where we should go at all. We can't manage. My 44 year – old sister, who lives with our parents, began to suffer from chronic insomnia and is completely exhausted while my mom cannot cope physically or psychologically with all this. The father refuses to cooperate, easily gets irritated and refuses to go to a doctor.

Please write me what I should do because I have a feeling that the entire family and I are jumping into a black whole. We cannot stop it by ourselves or to make it milder at least.

#####

Bogusia

Welcome to our club and ho in, honey.

I haven't said a word for a long time because I'm providing care to my mom who has Alzheimer's. Moments of aggression are behind me (Mom would chase my then 13 year – old daughter with a poker and a knife). There is one basic rule: don't let the doctors give you the bird because our health service is the way it is. You have to request a referral to a geriatric hospital (I waited three months). Assertively present the situation and don't let them give you the bird. Tell your father he's going to have a check – up exam. In private, tell the geriatrician what's the problem. They prescribed the medication and the dose so my mom is very calm now. You will read here and there that it's unacceptable for these poor people to be stupefied and drugged but take it easy. Your safety, the safety of your loved ones and, paradoxically, your father's safety remain the most important things. I administer Ketrel. All medications were prescribed in the hospital. It's fine with the aggression. I'm sorry for the poop thing. You can't do

anything about it. Every day I can find little surprises in various places at home. Of course, my mom says it wasn't her. Yu will manage. The final solution is incapacitation but you have to go to court. I didn't do it but my friend (her mom is ill too but she told me it is swift and then you can make all the decisions). Hospital and tranquilizers are rudimentary. You have to be strong and assertive. Trust me, doctors do not give you bird to such people. Documents, requests, running numerous errands. Also, line – ups – to a doctor, queues to a municipal office or to a municipal social security service. Three months of waiting (I also waited three months for my mother to be admitted to a geriatric ward and to be diagnosed). People, wait and think for a while. Does anyone care that we neither have the time nor the energy to do it? So tomorrow I'm taking a request form and I'm going to have my mom's level of incapacity evaluated. It will take

two hours, at least but who cares; I went there last week but only the supervising doctor
Czarna dziura. Nie umiemy sami tego powstrzymać, czy chociaż załagodzić na tyle by
can fill the form. And the same doctor is on winter holidays. He's lucky. To make it
ridiculous, this doctor saw my mother in the beginning some two years ago. He only
signed down a referral to a geriatric hospital but later on his care was limited to writing
prescriptions. You can see it yourselves how important his role in our lives is. Then I'm
going to take the form to social security office. I don't know how much time it's going
to take but perhaps one hour. And probably in three months time I will be able to receive
the invoices for the diapers and the medication. And in April the taxation office will
reimburse the money if I happen to spend more than 100 Zł on her. I can feel that with
this kind of money we can really get crazy. I fell like crying. Sarcasm is all I'm left with.

#####

Krysia

Five years ago, in 2007, the neurologist and psychiatrist diagnosed this disease in my
mother following brain CAT scan and an interview. It was shortly after her 80th birthday
party which we noisily celebrated in a restaurant. Then the doctor started to make me
aware and to help me get ready for this horrible disease. But I know I wasn't fully aware
of the real picture of his disease, it takes time. I remember the day when my mother
could not recognize me anymore and talked to me as if I was a stranger. My world was
ruined, suddenly someone who was so close to me, who used to be so warm and
empathetic became a stranger. She was present here but it was as if she was absent.
There was a human being but this human being was absent. She was here but her mind
was far away. With time, I began to accept the situation because there was no other way
out. The family, friends and others around us could not yet notice it but I already knew
what was going on with her. I would camouflage it and she would do it too.

#####

Martuś

Hello, in my mom's case the diagnosis was given some five years ago. I remember her coming home and saying that she is terribly ill, namely she has Alzheimer's. In the beginning I didn't care too much, possibly because "you don't die of it". My problems with forgetfulness were even worse and, thanks goodness, it's not painful. My mom would just visit a doctor, the illness didn't progress. The doctor said that actually it wasn't Alzheimer's and even if it was Alzheimer's there was nothing to worry about because there are medications for this. The bomb exploded two years later when our life evolved completely within just one month. The illness showed its ugly face, what it could do to people and I instantly realized what this jackass was all about. Actually, it was the entire family that got sick. I wish I hadn't let the doctors put my alertness to sleep. Anyhow, it wouldn't help but at least I lived two years unaware of what Alzheimer's really meant. Best regards.

#####

Net

Let me know if dramatic health deterioration can come in a day? It was like this in my case.....Mom, who has been living with me from May and has already been sick for a few years behaved reasonably well – she was calm, sit quietly and wasn't a problem for anyone. She was quite independent – with my hints – she would wash herself and do some minor activities of daily living. She was recently prescribed a new medication. She took it for one week and now we came back to the old one because we have it in reserve so the psychiatrist recommended that she take one medication for the first week, then swap and take the other for another week. After this new medication she became sleepy, she slept a lot during the day. She has been taking the old medication for two days now and yesterday's night was lost – neither I nor my mother slept a wink. She spent all night on getting out of bed and talking to me endlessly so I went to work feeling like a zombie.

The caregiver told me that today she didn't sleep during the day at all; she only wanted

to get dressed so that she can go for a walk. She was talking to me and to her mother who died in May and so on, and so forth. I gave her something to calm her down, now she is lying here next to me because I'm waiting for her to fall asleep – I have a lot of work for tomorrow and here she comes lying and still talking to me. She makes pauses and then talks nonsense again.

I'm horrified and cannot comprehend it particularly because it was all so sudden. I'm afraid the changes are irreversible (now she's laughing to herself out loud) so here comes another sleepless night...What could it be? I'm disoriented and frightened.

izagre

I started to look after my parents in 2006. My father got sick with lung cancer. My mum decided it was I who was to take care about the father. I'd always been Daddy's daughter and so I didn't hesitate a second and I took father to my house. I organised all the tests for him and I went with him for every chemo session. Everything was right till Christmas (?). Dad started to fall down and it turned out the cancer had spread to the spine. Dad was dying 11 days. He died on 11 January 2007 at 4 a.m. . I had arranged home hospice. I'm really impressed by doctors, nurses and volunteers. They had been really helpful. At the moment of his death I was alone with my father. In the morning there came mum (a very domineering person) and ORDERED!!!! me to call her son and inform him about dad's death. I'd always been obeying her. Her son came and they together were mourning in the kitchen while I went to arrange the funeral. I was coming to terms with all that for a year. I thought it was my fault. I thought I could have done much more. Now I now know I did all I could.

In 2010 I started noticing that there was something wrong with my Mum. The fridge was empty, every now and then, her phone or TV set was broken down (she just pushed a button on the remote and she switched off the phone). There was no light (fuses had been blown). I was going to and fro. I neglected my own home, my husband and children. After yet another telephone I decided to take mum to my place. As you may guess, her son was offended. And I did as I had said – I took Mum to live with us. She had been with us for three months and just out of the blue ... THIS MAY COME TO YOU AS A SHOCK!!!! March 2011, I came back home from work and could see that Mum was upset. She told me that our ways had diverged and that I was to take her to her home (in the middle of the week). I refused, I felt really exhausted because of the situation. Children, husband, household chores, work and to top it all my Mum's sulks. (These were the very symptoms of the disease of which I was unaware of). When I was at work her SONNY BOY called her and told her some rubbish. Mum packed her suitcases and went to her place on her own early in the morning. The SONNY BOY closed her bank account. He took all her savings and signed the account over to himself. He placed Mum in hospital and in his text messages he tried to persuade me to sign Dad's part of the house over to Mum. I replied that the very moment Mum was financially secured, I would sign the house over to her. Once he had stolen Mum's savings, he signed her pension account over to himself and brought Mum over in the assistance of the police. I wasn't at home (luckily for him). Mum wanted to go back with him and so he wrenched her savagely. She was bruised all over her wrists and back. He took her to my severely ill parents-in-law. She didn't want to come in so he grabbed her by her clothes and pushed her inside. He called me that I was to get Mum from my parents-in-law. My husband went there. They came back at night. To get Mum's documents and belongings I had to go to the police. He also fancied that he would make me sign Dad's part of the house over to Mum, then he would sell the house, take the money and bring Mum with the police. Unfortunately for him, I foiled his plans. Now, I can look at the back of his and it's all over. He spent Mum's savings on a car.

Mum's complaints were getting worse and worse, she emptied her bowels and passed water anywhere: on the floor in the kitchen, the living room, the bathroom. She took our underwear, my or my daughter's knickers, my son's pants, no matter what, from the drier. She hid dirty underwear wherever she could. Most often to my and my husband's bed. In the evenings I cooked dinner for the next day. When I came back home from work the following day, in the broth I had cooked there were floating fries, dumplings, frozen food and other stuff she had found in the fridge. Mum cooked dinner. Once she was washing up when fortunately my son returned from university. Water was overflowing – Mum had forgotten to . The worst, however, is that Mum cannot stand my daughter (14 years old) and she is verbally abusive and aggressive towards her. For three months after she had been diagnosed and put on a course of drugs, we could see some improvement. Now it's been all deteriorating. I'm sorry for having written so much.

#####

Wiosna

Grandpa is 90 years old. Up to 87 – 88 years of age he managed to do everything on his own, he was very active physically (riding a bike), well-read Nowadays. The disease has been taking away everything

Since the death of my Grandma ten years ago Grandpa had lived alone. He didn't want to move to our hometown, to my parents (that is to his only son). Everything was just great ... till when about 2 years ago there occurred minor incidents (delusions) ... and the first major attack. Grandpa's sister called and said that he came over to her on his bike in winter because someone didn't want to let him in to his house ... He might have fallen down a couple of times while trying to climb the ladder. We got into the car and went to take him back to his home. For the very first weeks after it had happened Dad lived with Grandpa from where he commuted 60 km to work and I spent weekends with Grandpa. Grandpa wasn't well at all ... he even didn't know how to take the prescribed drugs of which administration was described on a piece of paper, as if he didn't understand what it said ... At the same time, however, he was really strong, he read a lot and kept himself busy. He's been living with my parents for two years now. The two years have changed our life. My Mum is affected by an incurable disease, too. My Dad has to work. Grandpa is looked after by my Mum, the other Grandpa (who was treated for depression) and me, when I'm not at work (at the moment I'm working two days a week). Dad arrives home from work at 4 p.m. and then I go to my home and my Husband. We are emotionally worn-out and it all begins to affect our physical health as well. Grandpa needs to be lifted and taken to the bathroom. Sometimes, however, he says nothing that he needs to use the toilet. Needless to say, we all know the way it ends.

Sometimes there are bouts of aggression and viciousness. Every day at 1 p.m. Grandpa has his lunch. Sometimes he refuses to come and sit at the table, he wrestles with us – and at that times

he is incredibly strong! I'm not able to lift him, and what's more, he can pull downwards using all his body strength so that we could not lift him.

He often has delusions – he looks for some spoons, needles. The worst is, though, that he doesn't sleep at night. Dad is on the verge of endurance, he sleeps in the same room as Grandpa ... or it would be more suitable to say that he stays there since he cannot catch a wink because of Grandpa.

The drug dose (in a syringe) has been increased but night bouts have continued ... then during the day Grandpa sleeps off and Dad is at work. Back at home everyone is exhausted and nervous.

On the one hand, I cannot imagine life without Grandpa but on the other, I wonder how long can we live like that??

#####

Dora87

I want to share my story with you. I take care about my 63-year-old mum. For two years her symptoms have been escalating. At the moment she's got some problems with telling what she's been doing during the day, she cannot tell what film she saw at the cinema, what day it is. She generally has some problems with short term memory. I could give numerous examples but that's not the point. I'd like to get some support from you because I've been left on my own – the disease and me. I've got a partner who supports me – I do owe him a lot but I don't want to burden him with my problems – he is a fatherly shoulder to cry on but how much can he take? I really hope on your help and support or at least some talk.

I don't know what to do in a certain situation, for example soup poured out into the sink and why? Each time the question seems to pop up. How to control my emotions when I am accused of something? Each situation teaches me new lessons. I've been asking myself a question why me more than once. Why did it happen to me? I'm 25 years old and I try to be optimistic about the future but it's difficult at times. I am a very cheerful person but for some time now the smile on my face has not been sincere. My work has become my refuge. I feel safe there and no one accuses me of anything. My mum says I'm the nastiest one because I don't spend enough time with her, she is lonely and the only one she's got is the dog. Every trip, even for a day, means asking a question what to do with my Mum. I cannot forget about the situation and just go away. I work and I cannot spend 24/7 with my mum. Her condition has been deteriorating from month to month. My Mum was in the Centre in Ścinawa. Soon we've got a follow-up visit. I've done all I could considering medical care. But what to do next ... ?

I hope one day we'll find a good-willed person. We are her closest relatives and there are also some distant ones – her cousins.

I can't say a wrong word about them, they take her for some trips, but let's put it straight – everyone has their own lives. I take too much personally and I really tend to agonise over

something, and this is my true problem. My Mum, on the other hand, is a very rebellious person and she is the one who always has to be right. At the moment I cannot really imagine a stranger looking after her. She won't let it happen. So far, she hasn't had any problem using toilet and does it on her own. She has no problem moving round the area she knows yet away from her neighbourhood she loses the sense of direction. And so I worry in advance because the disease has been developing so fast ... and the onset wasn't indicative of Alzheimer's at all. It all started with writing down all the goings-on and asking all the time the same questions (which I patiently replied even more than five times) and hiding things – never ever in my life would I have thought of these symptoms as typical of Alzheimer's. I might have been unaware, though, I didn't know much of the disease, I wasn't really interested in the disease that did not concern me or my family! I tended to explain Mum's behaviours as usual at her age.

Mum used to be a very active person, she had her job, worked in the garden. She's been retired for 11 years now. After my grandma died she became very lonely and the only ones left were me and the dog. It is difficult to say whether she's been through a lot. she hasn't been spared by life but on the other hand she's been always coping. She's never been the life and soul of the party. For two years, the symptoms have been deteriorating – she has been having depression, losing sense of life, waking up at night; she hasn't read any books any longer. She's got mood swings. For a couple of years she's been affected by diabetes and is insulin-dependent. Two years ago we spent New Year's Eve together and on the following day my mum asked me what were our plans for the approaching New Year's Eve – I got really petrified. Since that very moment I've been looking for some help from specialists. My aim was to help her. When I think of the issues my peers tackle with, I just silently laugh to myself. Sometimes I hold it against her that instead of planning my own future I have to think of her. I doubt if I am able to shoulder such crippling burden of responsibility and duties. Please don't think that I pity myself but I do find the situation really difficult. I'm just afraid about the future and what it holds. For a year I've been responsible for all specialists she's seen, drugs, appointments; I'm my mum's personal assistant, as she calls me, and always on call. Apart from all the above, mum's been on antidepressants, cholesterol – regulating and diabetes drugs. Some time ago her hands started to tremble and she is at a loss for words. I don't know how but I'm coping, I don't think I have a way out ... someone has to take care of my Mum finally.

I do realise that it will be getting more and more difficult with each day. Mum is conscious and she will not accept a caregiver. I've been considering day care and therapy targeted at patients with Alzheimer's, just for the very 8 hours when I'm at work. I don't know though whether there is such a centre in Wrocław.

Talking about gas (stove) and cooking everything is under control. She sometimes burns something. She doesn't cook very often unless she prepares dog food. When she wakes up in the middle of the night, in the kitchen she can see smoke which actually is not there.

Spasmodic trembling of hands. Her handwriting has changed. She doesn't read any books – I think she doesn't remember what has happened or she just loses plots. She still does crosswords. She buys and 'reads' glossy magazines. When we practise reading comprehension, for example

Tomek is 12 years old and he has a brother, Łukasz, a dog, and a cat. When I ask her what animal Tomek has she cannot answer or she makes things up.

The worst thing is that every morning when I wake up I don't know what is going to happen later on during the day. What mood will she be in once I return home from work? Will she greet me joyfully ...?

I do my best to spend as much time with my mum and my boyfriend as I can so neither of them feels neglected. My boyfriend is very understanding and supports me in the situation. Although he has witnessed me giving vent to my anger and frustrations more than once.

It's really great to have you guys here and to share my bitterness with you and to know your point of view!

Best regards and have a nice day!

#####

Iwona

Hello again,

Before 2010 ended I had come across an old forum. I found myself in a trap or at least I felt so. I looked after severely ill cardiac 88- year-old mother and her 90-year-old sister. Last year in February, aunt broke her leg and during her convalescence and rehabilitation, first symptoms appeared. Soon afterwards she was diagnosed with Alzheimer's. First indications that there was something wrong appeared a bit earlier but both our lack of knowledge and aunt's reluctance to doctors made us underestimate the problem and let the horrible disease develop.

Aunt lived alone and she visited us – I live together with my mum – once a week or even more seldom.

I couldn't take her home because my flat is really small and there would be no room for an additional bed, not to mention a spare room. Besides, because of her health condition, my mum needed peace of mind, she shouldn't be annoyed.

When my aunt returned to her home from hospital I arranged care for her. Yet the disease was developing really fast – she walked at night, she wanted to go for a walk. When the caregiver tried to stop her, she became so aggressive that the caregiver had to lock herself up in a room. No one could sleep. All in all the caregiver gave up.

Then, I asked you for advice and although most of you told me to let aunt stay at home as long as possible, I had to place her in a nursing home. Since then, she's been there. Although the care they provide is pretty good, undoubtedly there have been no fewer problems and I have to go there quite often, for example when she falls down because she tries to run away and she is highly inventive in this matter.

When we could still reach her, she was pretty satisfied with her stay there; she had befriended a couple of ladies, the care was good and I also arranged a caregiver who went and visited aunt three times a week. Now, when we can hardly reach aunt, the caregiver goes there twice a week. She collects laundry and performs minor care routines. And so I spent my life going to and fro, between my mum, who luckily was in a good mental condition and my aunt, her affairs and a lot of red tape. For 11 years there's been an inheritance case in the court. My aunt's husband had children by his first wife. Aunt's flat is a real problem because we cannot sell it because of the filed case. And the flat requires some major repairs; the roof is falling apart, pipes are being exchanged or some other works are being done, or we have to go there because an expert is to estimate the household movable assets.

In my worst nightmares I wouldn't have thought that fate was to bring about something even more mischievous.

For two weeks now my mum has been having memory impairments. I suppose she might have overdosed her cardiac drugs (last year in February her cardiac performance was 30%) that resulted in a serious decrease of blood pressure and she's been treated for hypertension that in her case is really dangerous since she's got aneurysms.

She presents short-term memory impairment, she doesn't remember happenings that took place 5 - 10 minutes ago. I've taken her drugs away from her and I administer these, that is the cardiac drugs. On 22nd December and 9th January we saw the doctor who said that in my mum's condition had had to result in such a situation and she referred us to a clinic for Alzheimer's disease patients. Mum has become indifferent, she sleeps a lot, she is unconcerned and bemused.

We followed already established paths when my aunt developed the disease thus on 28th January mum will have head CT and vital diagnostic tests done. Unfortunately, my mum had to be diagnosed and treated privately.

My aunt did have some savings. All of these were spent on her treatment and stay in the nursing home. By the way, the bank clerk, siphoned quite an amount from aunt's account and at the moment she faces some charges and an investigation is carried out by the bank. It turned out that had stolen money not only from my aunt. No one knows, however, when it will end. I faced a double tragedy. I had to look after two close persons. In April Mum will turn 90 and my aunt is 92 years old.

I'm 64 years old and retired. I've set up a one-person business to have some extra income to my pension. Once a week I have duty hours, 5 hours, in a foundation and once a month I have to go to see my customer outside Warsaw.

How shall I live? I don't know, I cannot sleep, no tranquilisers seem to work and improve my condition.

I've got some pets at home and they are the ones who bring some happiness into my colourless life. I'm afraid about them as well. It would be reasonable to pass them into some good hands but I wouldn't stomach it.

I feel as if I was sinking. I don't know how to live

I seem to be overwhelmed by the amount of problems I've been facing. My aunt's first manifestations were very different from the ones of my mum's. I don't want to go into much details again but my mum presents with what follows: she feels the worst in the morning. she cries, says she is really weak and that she wants to die. Being treated for hypertension for years, in the morning her blood pressure drops below 90 (the top number). And she doesn't remember if she's taken drugs. The drugs are her phobia because she's been avoiding taking any medications. Whenever she felt better (physically) she rejected taking them, and this was yet another problem.

Now, she demands drugs. I give these to her and in three minutes she doesn't remember that she's already taken them. I explain everything to her and in 5 minutes there she comes again that I haven't given drugs to her and why I have taken them away from her.

Then she goes to sleep and sleeps till 2 p.m. . When she wakes up she becomes a different person – she behaves AS IF she wasn't affected by the disease, and I say 'as if' because it's possible to talk to her although she doesn't remember about the drugs.

On 28th January we've got an appointment with a neurologist. I've been also considering seeing a psychiatrist.

We've got an appointment in a national health care clinic scheduled for 28th May ... My mum has been confused, and she herself says so whenever she is better in the evenings.

I've read on the Net that symptoms of dementia and confusions may be as well brought about by dehydration.

Mum has been on water pills. Shall we cut down on Furosemid (a diuretic drug), another pulmonary embolism may occur.

It seems to be a vicious circle and I've become really helpless.

She's got an appointment with a cardiologist scheduled for 1st March, a neurologist for 28th January. I think I'll wait with making an appointment with a psychiatrist till we see the neurologist.

I've hidden the drugs away from my mum and she doesn't take them. I've hidden the drugs in such a place that she won't find them.

I suspected she must have overdosed the drugs because she forgot that she'd taken the prescribed dose and so I took them away.

Now she is arguing with me about the drugs. Before she was really reluctant and whenever she felt better she stopped taking some of them.

Now it has all changed. She keeps asking me for these.

I gave her a three-dose pillbox. There I put drugs that she should take currently, and in the evening I put the drugs that are to be taken on fasting the following morning. Then I give her all the remaining drugs as has been prescribed in due course.

I can also see the way weather affects my mum.

I've been wondering about one thing, though – it all happens in the morning. At that time everything is a blow, she doesn't remember a thing, she asks about everything a couple of times, cries and becomes anxious.

In the afternoons, at about 5 p.m. everything becomes normal apart from the fact that she doesn't remember that she took her drugs at 4 p.m. . You can chit-chat with her, she watches TV and does crosswords.

I haven't the faintest idea what it all is about.

#####

Iss

My mum has been getting worse and worse and I don't know how to help her and myself. We live in Świętochłowice, in Silesian Voivodeship.

I don't know what to start with. Maybe I'll start with the fact that I've got a 22-year-old autistic son with Crohn's disease. I bring him up on my own. I'm an only child. My father died a dozen or so years ago. When at Easter 2011 we had to go to hospital because my son started to bleed from the guts I noticed that my mum didn't really cope with the usual stuff. I know I should've noticed it much earlier but it happened otherwise. During my son's stay in hospital I made a decision to change my flat for a bigger one so that it could accommodate the two of us and my mum in her own room as well. In September 2011 we moved flats. It was then when my son had such a severe flare-up of the disease that between September 2011 and July 2012 we didn't spend a month at home (I have to stay in hospital with my son 24/7, otherwise it is just undoable). During that time my son was operated on three times for his guts because it was impossible to stop bleeding. These months affected my mum very badly. Although she was provided with all the groceries (my cousin, who looks after my mum's sister with advanced Alzheimer's on daily basis, did the shopping), she ate so little that she lost weight and it became more difficult to reach her. Mum doesn't want to go and see the doctor. When I mentioned an appointment with a neurologist or a psychiatrist she told me that she wasn't stupid and if I didn't feel right I should see them myself.

In November 2012 when I was going to Warsaw with my son who was to have his drug given, my mum stayed at home alone and she fell down. She managed to call my cousin who called me and from a distance I had to supervise door unhinging and opening (I must say that my lack of common sense is limitless – to my horror I hadn't left spare flat keys with anyone). Two days

passed and my mum agreed to go to hospital for a couple of days because she couldn't walk. She was admitted to a neurology ward. Having performed numerous tests, doctors came up with the following medical history report:

The female patient was admitted to the neurological ward because she had collapsed, fell down without losing consciousness. On admission neurological examination revealed features of extrapyramidal syndrome manifested as cogwheel rigidity affecting all four limbs, gait impairment, gait abnormality, dementia syndrome. Head CT and Doppler vascular flow of cervical and vertebral arteries were performed. During hospitalisation pharmaceutical treatment was modified (selegiline and donepezil were included) that resulted in improvement of the patient's condition. The patient was consulted by a neuropsychologist and rehabilitated. On the day of discharge, the patient is taking small steps using a walker. The patient has been discharged home with a recommendation for further treatment in an outpatient clinic.

Before going to hospital mum didn't control passing water and she peed anywhere (in the bed, on the floor, or next to the toilet, providing she had got there). She was angry with everyone and the whole world., she screamed or cried, she saw things that weren't there. She didn't let anyone help her. Once she came back from hospital it was really great for about three weeks and then it started to get only worse and worse. Now, mum wets the bed, she often removes a liquid-impermeable undersheet or a nappy, she doesn't want to hear about a urinary pad, either. She sits or lies on wet sheets, she doesn't want to change into anything dry, and she doesn't want to wash either. When I try to help her she starts to scream that I'm allegedly murdering or beating her up, and so on. Today morning she opened her bowels and passed water in the cat's litter box which is just next to the toilet, so she could have missed it because she's been using the toilet standing for a couple of days. Unfortunately, in the evening she went to the toilet first and then to the bathroom. It is usually so that I go to the bathroom once she leaves to close the tap. But today it was different. The tap was closed. The very moment I entered the bathroom I could smell something foul. Under the bathtub I found her slipper with a piece of cloth into which there was wrapped poo. When I asked her why she opened her bowels into the slipper she said that I hadn't let her use the toilet and then she changed her mind and said that it wasn't hers and it surely was mine.

I've been writing all this wondering what to do. Sometimes she makes scenes and then a few minutes later she cries because her daughter (that would be me) wants to poison her with drugs. Sometimes I cannot stand it anymore and I just burst. I calm down after a while and I pity her When she is afraid to lie down on bed because there is a huge, black hole behind it, I put a bedside table there to cover the imaginary hole. When she thinks there is someone standing behind the curtain, I draw it back to show her there is no one there. But what shall I do when I hear that I've robbed her or that she is bruised all over because I've beaten her up?

Is it possible to treat a person like my mum against her will? Will the treatment work anyway? What will happen if I need to take my son to hospital again and unexpectedly, as it usually is – something bad happens, I get into the car and drive since there is no time to think.

Can anyone tell me what I can do to improve our life?

<http://forum.alzheimer-krakow.pl/viewforum.php?f=4&sid=3e3b310f1293f128f82cb9ac6cbb8358>

#####

marta.pytel@rovita.com.pl

Hello everyone,

My mum has been affected by Alzheimer's for several years now. For a year and a half I looked after her myself and so I stayed at hers' overnight. Then I hired a caregiver who stayed with her during the day, first for a couple of hours and then for longer. Then I moved in to my mum's but there was still a hired caregiver coming for the day (I work and I cannot afford not to work because I support the family myself). I was really exhausted because my mum didn't sleep at night. Then I hired caregivers who actually lived with my mum 24/7. Unfortunately, the caregiver submitted notice and I haven't got a new one. I've been searching high and low, asked in the employment office and placed ads in local papers and so far without any success. No one is willing to take on the job. No one has even called. I suppose I need to make the closing decision and place my mum in a nursing home. Could anyone share their experience with me? What are nursing homes like? What is the care there like? I will appreciate any help since I don't know what to do. Thank you.

#####

natalia

Hi there!

As most of you here I've come across Alzheimer's in my family. It is my grandma is under my charge. She diagnosed last year (2008). I do realise this is the very beginning of a long way. Grandma dresses and washes herself, she leaves home for a shop or to visit her family. On the other hand, when she goes to the shop for some bread, she doesn't buy it; instead of bread she buys yet another bar of soap, she tells far-fetched stories deprived of any common sense. Recently she's started to accuse my mum and me of theft. She forgets to eat her meals and when we put any food in front of her she claims that she won't manage to eat it (because she's already had three meals; sometimes, though, despite all her stories how full she is, she somehow manages to eat the whole dinner). I'm sure that you all know such stories thus I will appreciate any hints. I also realise that a solution to the problem is rather individual and often intuitive, but nevertheless I will appreciate any suggestions.

- 1) We don't really know to what extent grandma 'is aware and thinks reasonably' and so we wonder whether it is the moment to remove door locks so she couldn't close them. As I've already said, I know that each case is different, we, however, are afraid that she may make scenes because we do 'against her and to her disadvantage'. All in all, is any time the 'right' one to do so?
- 2) Grandma doesn't know she's been treated for Alzheimer's. She should see other doctors for regular checkups, though. Last time she had an appointment (at a neurologist's) and she almost insulted us and definitely refused to go there (if you've made an appointment, you should go and see the doctor yourselves). We've been wondering how to convince her to see the doctor, it's for her own sake?
- 3) We're afraid she may give out money or that someone may 'tap' because we have recently noticed that grandma has problems using cash. Would it be a good idea to pay her money into an account for safe keeping? We are also afraid that then grandma may think that we have stolen money from her and she may find us untrustworthy.

This is all I can think of at the very moment. I will appreciate any reply

Best regards and wish you all a lot of endurance.

#####

Maryjka

Sometimes I'm really fed up. For example when my Mum leaves my house and tells my older sister that she really doesn't like staying with me.

Mum, don't you realise that I could spend the afternoons when I pick you up from the Foundation in a different way? Don't you understand that sometimes I'd rather be somewhere else?

And then I just say to myself that my issue is to understand Mum and Mum has issue understanding the whole world. And I become humble.

#####

Minia

My grandma is 76 years old. For about 10 years she's been affected by the Alzheimer's. Till three weeks ago my grandpa had taken care of my grandma. They live in another city. Three weeks ago grandpa was diagnosed with stomach cancer and since then he's been in hospital in Poznań and grandma has been staying with us. The thing is that she doesn't know who we are, she knows, though, that our faces are familiar to her. She doesn't wash (we have managed to persuade her wash herself only a couple of times; she doesn't wash her hair either – she says she's already done it), she wears a fur coat and boots all day long (she says it is cold). For a

weak now, at about 3 p.m. she wants to return home. She takes her bag and wants to leave. Then we explain her that she is in Poznań far away from her hometown. Then she makes scenes, goes into hysteria, she says that we treat her as a prisoner and she starts to scream, threaten, and cry claiming that her house is just opposite. What shall we do in such situations? We lock the house and it's impossible to leave it without opening the entrance door with the key.

At the moment grandma is on HALOPERIDOL, a tranquiliser.

She dresses herself because she doesn't want us to help her but she, for example first puts on her tights and only then her knickers. She can make herself a sandwich providing everything has been prepared beforehand and is on the table, and she uses the toilet on her own. All these activities she can do on her own, she finds it difficult to do anything else. The worst thing is when she wants to cook anything, we need to have an eye on her all the time, because she comes to a hot pan and puts her hands on or in it. She often confuses words, for example school – pool, luck – duck and so on. She doesn't understand such words as 'grandma', 'mum', 'granddaughter', etc. .

On the other hand, when we want her to go and see the family doctor she strongly refuses and says that she's already been to the doctor and so she won't go again. We cannot take her anywhere nor she herself wants to go for a walk. She sleeps through the night and more and more often she gets up at about 2 a.m. and she washes up the dishes. This is not just typical washing-up; she just pours and sprinkles water all over the dishes and leaves the tap open. She listens to no one. Even grandpa doesn't have any influence on her.

We are really helpless.

We do love grandma a lot and we just want to live through this difficult period.

We would appreciate any advice.

#####

Bożena

At the beginning of her disease my mother-in-law behaved just as your grandmothers does. It was her strange cooking, dressing, continuous losing things, and so on, that made us think of the disease.

My situation is much worse since I am her daughter-in-law and she is the mother-in-law and needless to say everyone can imagine the mood when you live together in a small flat. Let me just add that my husband is an only child and my mother-in-law is a divorcee.

I had to talk the situation through with her family, tell them what was going on. Although she saw them every day they only noticed a small problem and started to explain her that she was to see the doctor and so on.

And she did after some time.

Once the disease had been confirmed, someone had to get down to tackling the situation. It may sound silly but she had to be moved away from such daily activities as cooking, we explained it to her that it didn't make any sense to cook just for one person and she somehow took it in. Then we had to buy a new stove and no matter what she did she wouldn't light the burner.

She also needed some assistance in dressing because she dressed the way your grandma did. Without asking her permission I became in charge of drug administration. I just took them and that was it. I followed the doctor's recommendations as to drug administration because she had taken even her blood pressure pills anyhow. Once we even had to call an ambulance and she was taken to hospital. So the drugs topic was out of question. I had to take her to the family doctor who really looked down on me and often asked what I'd come for. I had to explain the situation not to be excused from the consulting room. I had to overcome myself to wash her. I just had to do it. I helped her to go into the bathtub, she washed herself and then I washed her hair.

The worst experience I can recall was her often using the toilet! All the time!

Then the dirt. Dirty door handle, lavatory bowl, and the floor. To wipe she sometimes used her own hand instead of toilet paper. She washed her knickers in the lavatory bowl to where she'd opened her bowels or passed water! It was horrid!

Having guests was the worst. I had to secretly check on the toilet and what condition it was in. My daughter was little at that time. I had to explain it to her that whenever she saw a dirty door handle she was to let me know.

And so we managed to live through our daughter's first Holy Communion that I had prepared myself back at home. Permanent checking. The following morning there must have been no toilet paper and I smelled this horrible odour. It came from her room. Everything was soiled She emptied her bowels on the carpet, smeared it all over the bedding, carpet, and even curtains. Just a small gift

Some time afterwards, we had to start using nappies because the situation had got out of control. And yet another horror! How to explain it to her that she shouldn't take it off? Not to tear? I put a nappy on and anyway everything was dirty because she somehow managed to take the content out.

So I had an idea to dress her up in a sort of corset (for elderly ladies, something like a swimming suit) so she couldn't put her hand there and she didn't know how to take it off. And it worked!

At the very beginning we padlocked the toilet door not to bring about taking the nappy off, we thought some reactions were lifelong. It looked really weird and funny for those who came to visit us, but what could we do.

And now, just as I've written earlier.

Take care!

#####

Matsu

In my case it was a progressive deterioration of Grandma's physical and psychological condition. I viewed it as something more or less natural (?).

When Grandpa died, Grandma got the first stroke from which she recovered with minor damage and thus neither us nor Grandma could notice any changes, we just missed the disease onset. We downplayed all the special effects and peculiarities as Grandma's brain was damaged after stroke, as she wasn't getting any younger, as everyone may forget, as we lived only two streets away and every now and then, more or less regularly, someone popped in at Grandma's. Besides her girlfriend was quite a character and except for crazy ideas she had a great influence on Grandma.

The moment there appeared anxiety states, delusions, trips to the cemetery in the middle of the night, confusion we started to look for a bigger flat so Grandma could live with us.

It must have been 2006. I was 20 and a first year student. I must say that enduring attachment to Grandma was getting strenuous. At that time I was thinking of getting my own flat, seeing the world, and so on. Once I went to see my Grandma (I remember as if it was today – I bought myself two beers, a packet of cigarettes, gummy bears and I went through the park so I had some time to eat and smoke). I found Grandma lying on the floor crying and mumbling. Ambulance, hospital and the second stroke. Grandma had all possible tests done – apart from stroke-caused damage, clinically apparent Alzheimer's.

When she was discharged from hospital it was bearable. Taking turns with my Mum and a caregiver we were spending whole days with her. At night she was alone. Before leaving we'd turned off the gas supply and so on. Then we stayed at night as well. Then we found a bigger flat and then it turned out there were some problems swapping co-op flats, then the family accused us of wanting to snatch her pension. And then, finally we managed to settle everything, and then there was 14 February 2002 and you know what happened

I've finished my studies, I've got work, there are two of us to look after Grandma and my father as well, but he won't change a nappy.

Most of my friends have abandoned me. Only few have left.

My beloved one hasn't held out. I'm not surprised.

I can forget about my own flat (I have no twinge of conscience at all but I just cannot afford it).

In September 2005 I spent a week barbecuing in the countryside. I like strong vodka.

Now my Grandma is in a nursing home, the situation has become unbearable. I thought it would change yet ... I've become dreadfully indifferent. I just don't know how to pull myself together.

#####

Sobek

My wife looks after her father affected by the disease. She's been doing it on her own for more than a year at my father – in – law's house. Because he doesn't live in Kraków, I've been seeing my wife only at the weekends.

There, everything is submitted to him – to provide him with the best care and comfort possible in the widest sense of the words. At all costs and with any mercy.

At the moment my problem is as follows: how to help my wife not to lose touch with the ordinary world and daily life, so that she could keep right proportions and was ready to return to daily life. Continuous 24/7 attention to one matter – that's what an affected person require – must affect a caregiver's personality. I do realise it but don't know what to do and how to prevent it.

#####

Raparagazza

My grandma is a person affected by Alzheimer's and we've got quite a similar problem with our grandpa ... he wants to be self – sufficient and is afraid of asking for help. He blames himself for preoccupying us with his problems and taking up our time. Recently, Grandma's condition has deteriorated and Grandpa doesn't cope on his own ... and so we help him with Grandma but are helpless in the face of all his problems. I know that relieving him at least partially is good and advisable. Yet it seems to me that he has broken down even more because he's lost belief in himself that he can cope on his own! How can I help him, how advise him without deepening the state of helplessness ... I'm afraid he may completely break down! This is a very difficult situation ... a person with a fully developed Alzheimer's is still very strong ... they attach the caregiver, make them dependent, and have control over them – to the extent that one day the caregiver stops thinking about themselves! Just as you are saying ... everything is submitted to the affected person! And I don't know if there is an answer to the question ... how to explain a devoted caregiver that they should also think about themselves ... since it 's shameful to think about oneself if the dearest person in the world is diseased and in such a bad condition. I'd like to say that there is an easy way out ... let the others get engaged as well. On the other hand, judging by my own experience, I can see that this solution has underestimated my grandpa's psychological condition

Maryjko, I love my grandma the same way I used to ... unconditionally and this seems the only means to cope with difficulties of living with the disease and living as such.

Sometimes it is not so easy to 'take the affected person to one's flat' ... my grandpa is too stubborn to do so ... you can't teach an old dog new tricks ... yet it won't solve the problem of emotional attachment.

Best wishes to all of you

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karolcia

So at the beginning when we learned about the disease, my grandma kept only forgetting things, for example, her way home or names. It happened seldom, though. The neurologist diagnosed her with Alzheimer's. For a month her condition has been deteriorating and we're afraid what will happen next. My Grandma spends almost all days in the toilet. She says that she needs to pass water very often and that she's got 'collywobbles'. She goes to the toilet every 5 minutes and you just cannot wash yourself. She's been on Yasnal, memotropil and antihypertensive drugs. Today she's had blood and urine tests done, maybe these will indicate something. We don't know how to cope with the situation – she doesn't let us sleep at night, she goes to the toilet all the time. How to stop this? Pretty often she opens her bowels and passes water right on the floor and when caught red-handed she denies it all and starts to cry that it hasn't been her ... what to do then? How shall we behave in such situations? She's started to wear a nappy at night and we've explained her that she has to pass water into the nappy. Yet she doesn't understand what a nappy is for and takes it off. Recently, she's lost her appetite. Whenever I make her breakfast or anything else to eat she says she needs to use the toilet and forgets about the food. It's happened twice that she left home to search for the toilet. Tomorrow I'm seeing a neurologist. Maybe they will prescribe some new drugs but which ones? As far as I know, Yasnal is the best drug available on the market. I must say I find it emotionally and physically difficult. We take turns with my mum to take care of my ill grandma and we both lose it. Besides, I'm pregnant and I shouldn't get nervous every day. Does anyone have a slightest idea what to do and how? You yourselves might have been in such situations? Maybe a nursing home?

Just please help us, I will be very grateful. Best regards.

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Hello everyone. So I've been to the neurologist with my grandma today. I had been waiting for more than three hours before they saw us in the consulting room. She kept talking about the toilet all the time and she repeated the same sentences all the time. No one let her out-of-turn. Everyone there was ill but no one with Alzheimer's! It was a real torture for both of us. When our turn came, a very nice old lady started to examine grandma. Grandma didn't know what was going on and I'm not surprised at all. She's been put on Estazolam, a tranquiliser, and a sleep-inducing drug. The neurologist was disturbed by the fact that grandma got a stooping posture and that she wasn't able to keep her head upright. And so she referred her to a neurology ward for diagnostic tests. And do you know what the most pathetic thing is? Having got through to hospital in Kołobrzeg (that's where she'd been referred to) the doctor told me that their CT

scanner was broken down and of course they would admit her to the ward but wouldn't run any tests. Why on earth the other doctor had referred her in the first place? In Koszalin – the same – BROKEN CT SCANNER! Two nearest towns and my grandma won't be diagnosed unless she goes to Gryfice, where she will have to be left because my parents both work and thus will not be able to see her every day. This is ridiculous! How can anyone let such situations happen?! Let me just add that grandma's condition has been getting worse and worse day-to-day. 😞