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# A Case Study of Cognitive – Educational Support for Elderly Female with Alzheimer's Disease

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## Abstract

Care and support for elderly persons is crucial issue for any cultural ground and any country. Special pedagogue (Special educator) in contemporary Polish university realities is person who has learnt while studies and qualified about support of persons with disabilities during life cycle. This mean, special pedagogue is or can be prepared to support persons since early childhood until late adulthood. This article is non-clinical, ethno-educational case study of individual, cognitive-educational, home-based support, conducted for 30 months by undergraduate female student for female diagnosed with Alzheimer's disease.

The case study is description and analysis of individual home-based, cognitive– educational support as an alternative to day-care facilities group support. Study neither examines the influence nor gives quantitative assessment of cognitive-educational support. The study and support raised in the beginning one question: what is the proper way of home-based cognitive-educational support for female in first stage of AD?

In the case study two key informants participated: Fiona Fiedler age 77, who received regular cognitive-educational support and her husband Fred Fiedler. The 3<sup>rd</sup> informant was Roksana Urban herself who had two roles: data collector as participant observer and regular support person working with Fiona. Personal data of study participants was coded and encrypted by me, ensuring level of wellbeing for participants and ethical considerations of data collection.

The results indicate that individual, home-based cognitive-educational support was proper alternative to the day-care based cognitive group treatments. Case study also indicates the importance of home-based support for spouse of person with AD - Fred Fiedler. Moreover, results indicate general positive attitudes to cognitive-educational support and wellbeing of Fiona Fiedler with AD while disease makes progress.

**Keywords:** Cognitive-educational support, home-based support, learning, care, late adulthood, female, dementia, Alzheimer's Disease (AD), qualitative case study, participant observation.

## Introduction

Alzheimer's disease, which occurs in the family undoubtedly, causes the crisis and the various reactions to it. It triggers helplessness and gradually the desire to organize help, support in day care facilities, long-term care stationary centers or at home. Sometimes, when there are no close relatives nor friends and spouses, looking for support is more difficult. A good first step is to go to the universities which in Poland implement a form of student volunteering.

The following case study is an illustration of educational techniques and support, enhancing the cognitive abilities of female in the early stage of AD, assisted in the years 2010 - 2013 by a female undergraduate student of Special Education and then a graduate of the Scientific Information Library Science and Librarianship, Press Studies at Nicolaus Copernicus University in Torun. Techniques of support are issues related to: the sphere of language connected with broadening and consolidation of vocabulary, orientation in time and exercises involving identical elements merging in pairs as well as math exercises.

Process of organization of the support started in beginning of November 2010, when I first met Fred Fiedler, husband of female with AD. He asked me for finding volunteer student, who would help taking care for his wife and support her cognitive skills. Paper contains data collected by Roksana Urbanco by end of November 2010 to end of May 2013 while supporting Fiona at home for 30 months.

## Review of Literature

**Defining Alzheimer's disease:** According to Leszek<sup>10</sup>, Nowotny et al<sup>13</sup>, Parnowski<sup>14</sup>, Babusikova et al<sup>1</sup>, Lu and Baudau<sup>11</sup>, Barcikowska-Kotowicz<sup>2</sup> etc., Alzheimer's disease (AD) is a degenerative disease, clinically characterized by progressive, irreversible mental deterioration. AD is responsible for about 60-80% of all dementias<sup>1</sup>. Dementia, according to Parnowski<sup>14</sup> and Lu and Baudau<sup>11</sup> is a "syndrome of symptoms caused by brain disease, usually chronic and progressive. This causes a cortical dysfunction. The main symptoms of dementia are associated with impaired short-term memory and long term

memory, impaired abstract thinking, impaired judgment, personality changes, cortical dysfunction (aphasia, apraxia, agnosia)". Lu and Blaudau<sup>11</sup> indicate that "dementia while the general term, describes the loss of memory and intellectual abilities serious enough to affect daily life for people suffering".

Authors cited above agree that AD, a progressive and unfortunately bad prognosis brain disorder that proceeding, is leading to a condition called dementia. For this reason, the authors Lu and Blaudau<sup>11</sup> indicate that the word "dementia" is sometimes used interchangeably with the term "Alzheimer's disease". However, authors notice that there are other types of dementia associated with a variety of factors. Lu and Blaudau<sup>11</sup> write that AD is not exclusive to Americans. Worldwide there were more than 26 million cases in 2006. The number of people affected is expected to be more than 100 million by 2050.

According to Gabrylewicz<sup>8</sup>, each year is recognized worldwide as 4.5 million new cases of dementia. According to various epidemiological forecasts, including the World Health Organization, the number of patients exceeds in 2040 to 80 million. Gabrylewicz<sup>8</sup> notes that Polish society is aging as well and that "the proportion of the population aged over 64 years was in 2010, 13.4% (5 157 317). The life expectancy in 2010 was 75.85 years (male 71.88 years, female 80.06 years). Studies on the prevalence of dementia in Poland showed that its prevalence in the population of people over 65 years of age ranges from 5.7% to 10%." The author draws on the results of epidemiological Polish studies which estimated number of people with dementia in Poland in 2014 since 300 000 to 500 000 cases.

Babusikova, Evinova, Jurecekova, Jesenak and Dobrota<sup>1</sup> wrote that "dementia is a common name for progressive degenerative brain syndromes which affect memory, thinking, behavior and emotions. Dementia mainly affects older people, although there is a growing incidence of the cases that start before the age of 65. After age 65, the likelihood of developing dementia roughly doubles every five years. Dementia affects 1 – 6% of human population over 65 years and 10 – 20% over 80 years".

Nowotny et al<sup>13</sup> write that "AD is generally diagnosed after the age of 65 years, when it is referred to as late-onset Alzheimer disease. The condition affects 5% of the population aged over 65 years and more than 20% of the population over 85 years. Only 10% of all persons diagnosed with AD develop symptoms before the age of 65 years. They are said to have early-onset Alzheimer disease and approximately 10% of these early-onset cases have a familial form of the condition which is transmitted as an autosomal dominant trait."

Nowotny et al<sup>13</sup> continue that in case of AD "the aetiology for the vast majority of cases is unknown. It is likely that

AD represents the final degenerative pathway initiated by a number of genetic and environmental factors".

### Stages of AD and characteristics

**First stage:** Barcikowska-Kotowicz<sup>2</sup> shows the three stages of AD. The author writes that the first stage of the disease usually lasts 2-5 years. The duration of this stage depends on many factors: genetic and environmental factors, including the efficacy of treatment taken. Most patients in Poland have no proper treatment from the onset of disease. The leading symptom of the disease is memory impairment. The author believes that "at this stage of the disease is widespread forgetfulness by patient of names, titles and content, just read books. The patient participates in the conversation, but is looking for words, lacking readiness of speech. He repeats the same phrases and the same story many times. During this period it first appears difficult to plan the day. Person with AD forgets about paying the bills, begins to express the problems with existing obligations at work, productivity is reduced, the patient needs to devote much more time to perform tasks that previously did not cause major difficulties to him/her". The author continues that "it is estimated that only 20% of patients in the first stage of the disease in Poland have properly established diagnosis by a physician. Lack of recognition means that patients are not treated. So do not get the benefits of modern medicine, slow build-up of symptoms by a few dozen months and sometimes longer. Failure to recognize the causes likewise numerous misunderstandings and tension in the family; failures to meet the patient's needs by environment is treated as arising out of laziness, malice or lack of respect".

**Second stage:** The second stage of AD, according to Barcikowska-Kotowicz<sup>2</sup> takes the usual "longest stage of the disease; It may take from 2 to 12 years. The memory of the patient is significantly impaired. Start also significant gaps in memory for past events. The patients may not remember the names of all their family members. The author writes that "in the second phase of the disease about 50% of patients' exhibit abnormal behavior. Patients tend to be aggressive, even physically. There is an annoying symptom for the caregiver - unrestrained walking. Sometimes forced crying or, less frequently, laughing. Some patients have psychotic symptoms: pathological suspiciousness, delusions about stealing, abandoning delusions about putting into a nursing home, or experiencing visual hallucinations. Often are present the rhythm problems of the day; the patient does not sleep at night and is excessively sleepy all day. The patient is terrified to be alone even in seemingly a familiar environment. Slowly she/he is starting to eat first one by cutlery, then by hand. Persons with AD begin to have problems with the control of the sphincters, impoverished speech. The patient ceases to be alone to dress and wash. In the last period of the second phase of the patient ceases to recognize the caregiver, even if his close family".

**Third stage:** The Third stage of AD by Barcikowska-Kotowicz<sup>2</sup> is characterized as following. "Duration of the third stage largely depends on the quality of care, usually lasts 1-3 years. The patient says single words; contact with her/him is limited to performing the simplest commands. She/he must be fed, does not control the sphincter, using diapers day and night. No signals of hunger or have eating disorders. Fewer and fewer moves, she/he spends most of the day sitting, then lying down, until finally being immobilized in bed, although there is no paralysis. Sometimes there is the cry of the night, or monotonous sounds of the day. She/he does not recognize the caregivers, even the closest family members".

**Memory impairment:** According to Parnowski<sup>14</sup>, the early stages of the process of dementia are characterized by cognitive impairment, among other disorders of attention, perception, thinking, planning and communication. It is the cause of the deterioration of well-being, loss of vitality, emotional instability, personality changes and difficulty performing everyday tasks. However, early identification of dementia may find the difficulty associated with impaired memory. The difference between benign senile forgetfulness and memory disorder with dementia is not fully understood. In contrast, given that the early memory impairment in dementia syndrome is characteristic: putting the wrong things, the inability to find them, increasing the need to check their operations, the repetition of comments and questions, the beginning of the story are forgotten shortly after its launch, the difficulty in the story telling, for example, films or books, difficulty in location, things are done repeatedly, most recently stored information and operations are forgotten and the messages are not forwarded.

Parnowski<sup>14</sup> points out that "in the early stages of AD damage is the main short-term memory (forgetfulness within 15 seconds to 2 minutes). Memory of past and current events in this disease is damaged at the earliest but this is done gradually. It is believed that language disorders occur in the later stages of the disease. Include disorders of naming, the meaning of words, grammatical simplification. Manifests itself find difficulty in finding words, naming objects and issues, disorders, difficulties in transmission of information and description of the event, reducing the length and difficulty in terms meaning of the words".

**Personality changes:** During the progress of AD, person starts to manifest changes in personality. Parnowski<sup>14</sup> considers that the personality change occurs in 75 - 80% of patients with AD and it grows as the deepening of the disease. It was found that patients had less likely establish contact; they are less confident, less mature, without energy, unhappy, irritable, less affectionate and attentive. Families of patients observed a rude behavior, loss of enthusiasm, increased feelings of guilt and suicidal ideation. Personality changes are also characterized by reduction initiatives, the rejection of existing interests,

reinforcement of attitudes, excessive cheerfulness in the wrong situations and loss of empathy. In persons with AD may also appear, according to the author's, delusions and hallucinations.

### Case study

The following ethno-educational case study, based on participant observation, refers to performed for 30 months individual, home-based, cognitive-educational support for female— Fiona age 77-80 with AD. Medical diagnosis of Fiona was determined gradually in the years 2006-2007 when Fiona was 73-74 years old. Based on Barcikowska-Kotowicz<sup>2</sup> characteristics, it can be noticed that at the start of the support by Roksana, Fiona was in the first stage of AD.

**Sampling:** Attempt to participant observation, conducted by Roksana, was chosen purposely. They were Fiona, a female with AD, Fred, her husband and Roksana, who also ran an auto-observation, which wrote down the notes. The person collecting the field data was mainly Roksana Urban, co-author of the article.

**Fred:** The beginning of the meeting with the problem of assistance to persons with AD began at the beginning of November 2010 in the evening, when during my office hours and consultations time at the university knocked on the door and an older man asked me, the supervisor of Students' Scientific Circle – Special Education Section at FES at NCU, for finding a student volunteer to support and help his wife. Fred motivated request that his wife was placed for a few weeks (as participant) in the daily support center for patients with AD and she very badly endured the daily stay. She usually returned home scared and in a bad mood. Fred was disappointed with the quality of support offered in day care center and clearly concerned about the fate of his wife. He was referring to the fact that the patients in the ward of the daily support were in various stages of the AD disease progress and their behavior strongly disturbed and stressed his wife, who was in the early stage of the disease.

Husband of wife with AD, showed a significant concern and he really wanted to find the right student volunteer. I was greatly moved and realized that the task is difficult even though the students eagerly participate in volunteer work, especially being able to support the children or young adults with intellectual or developmental disabilities. Fred left his e-mail and left my office. Within a few days I sent about 200 e-mails to students of different courses and unfortunately no one replied for my request. Fred wrote me an e-mail with questions. After about 2 weeks, unexpectedly I received e-mail from a female student, member of the Section of Special Education, in Students' Scientific Circle - Roksana Urban. I gave her the address of Fred and Fiona. This was indeed the only person for 200 e-mails who signed up. This gave me also an image of tensions and potential fear caused by the associations of

disabilities in late adulthood and AD.

**Fiona:** Fiona is a married female, the wife of Fred. She had for year's successful career as an employee, worked in the design office. She also spent many years with her husband abroad. At the commencement of the meetings with Roksana, Fiona was 77 years old and at the end of support she was 80 years old. Diagnosis of AD was determined at the turn of the year 2006-2007. In February 2011, Fiona had neuro-speech-therapist's diagnostic examination which identified her current, potential areas of support. Neuro-speech-therapist Fay Fuller<sup>5</sup> described Fiona's state of cognitive functioning as "deep communication of a sensory aphasia trans-cortical. Comprehension of single words, sentences, commands, grammatical structures and content of stories disturbed". "In terms of spontaneous speech prolixity, information poverty, low resource specific vocabulary, profoundly impaired ability to use conceptual and semantic resources." "Fiona repeats up to 3 words and simple sentences correctly. Generating opposites disturbed. Test MMSE pentagons correct. Clock drawing test was invalid. MMSE 8 shows the profound dementia."

Roksana writes in her field notes "first meeting with Mrs. Fiona and her husband was a purely reconnaissance. After an earlier telephone confirmation, we met in the apartment of Mrs. Fiona and Mr. Fred. Mr. Fred was a man of organized, resolute and determined, so far as possible to inhibit disease progression in a spouse. Ms. Fiona while, was a person with a pleasant disposition, quiet. From the first minute could be seen that she has problems with eloquence, as repeatedly refused to join in the conversation. As demonstrated by our subsequent joint walks, despite her advanced age (about 80 years) she retained good physical condition".

**Roksana:** Roksana is the student researcher collecting observational data, a volunteer tutor implementing cognitive-educational support for Fiona with AD. Roksana Urban initially began volunteering and working with Fiona on 23 November 2010 while she was undergraduate student of the third year of Special Education studies at the Nicolaus Copernicus University in Torun. Gradually, after several meetings, Fred suggested Roksana, remuneration for work. Volunteering has been transformed in part in paid work. Roksana was and still is a calm person, serene, cultural and emotionally balanced. I knew her well because she participated in my two university courses. I knew that she is a responsible and conscientious student, reaching good results in studies. I knew her also well from participation in the Students' Scientific Circle - Special Education Section, I supervised since February 2004.

**Data collection:** Data collection took place from the end of November 2010 until the end of May 2013 in Torun, a city of more than 200 thousand inhabitants, located in the North-Central Poland. Extensive observational, textual data was collected by Roksana during ongoing support activities

and meetings with Fiona. Roksana sent me a report of meetings with Fiona, which accounted for a total of 45 pages of A4 size and contained a total of 31 photographs of therapeutic materials and prepared exercises. In the report, there were 40 scenarios of meetings together with photographs. Roxana did not perform any photos during the meetings. Data collection took place at least 2 times a week for 60 minutes. In total, Roksana took meetings with Fiona and her husband Fred for 30 months.

**Ethics of Data Collection:** Data collection was based on the involvement and support of the study and obtained by Roksana consent from Fiona's husband Fred, her legal guardian. Fred agreed to describe the process and the support of his wife, agreed for writing both the book and the article. He was very supportive also while writing this paper, giving supplementary needed data. Personal data of participants in this ethno-educational case study was coded and encrypted. All data begin with the letter "F". Encrypted name was also performed for in the name of neuro-speech-therapist. According to the diagnosis, Roksana prepared a plan to cognitive-educational support for Fiona. The ethics of data collection was based on the concept described by T. Rapley<sup>15</sup>.

**Data Analysis:** Case study is based on content analysis of qualitative data, collected by both authors of the case study. Main analytical technique is based on concepts of documents and case analysis by Rapley<sup>15</sup>. The analytic process involved the analysis of formal and informal documents, what means documents formally constituted as forms of neuro-speech-therapeutic diagnosis. The documents also included informal, personal documents and 31 photographs of which 2 are included to the paper. Furthermore, case analysis of the data contained data produced by Roksana, including the scenarios of meetings and support, comments, notes and comments on the problems while the execution of tasks by Fiona.

**Assumptions and framework of cognitive - educational support of Fiona with AD:** An important point of reference when building support for Fiona was indications detailed by neuro-speech-therapist encoded as Fay Fuller<sup>5</sup>. Her indications have been announced on 02 January 2011, so after about 2 months since Roksana started volunteering and support for Fiona. Indications of neuro-speech-therapist Fuller<sup>5</sup> focused on the following areas, all of which were a huge part of language exercises. Fuller<sup>5</sup> recommended exercises on speech intelligibility such as naming objects from the environment and shown in the pictures, exercises of automated verbal strings, completion of proverbs, comparisons and phrases functioning in everyday language, the type of word puzzle solving truth-false and exercises both, semantic verbal fluency as phonological, consisting of exchanging as many words ex. the greatest number of animals or words that start with the letter "k".

Fuller<sup>5</sup> also recommended "exercises such as verbal auditory memory, repetition of simple words and complex sentences, improving orientation allo - and self-psychological (awareness of the self, awareness of the time, place and space). In addition, short-term memory exercises (ex. What you did before?), autobiographical (ex. where did you go to school?), semantic (ex. What is the capital of Poland?)" were performed. Indications of Fuller<sup>5</sup> contained also useful, practical observations which benefited Roksana. Among them were the following: recommendations as speak to Fiona using short sentences, with the slow pace of speaking. In addition, speaking to Fiona saw movements of the mouth.

Fuller<sup>5</sup> also advocated: loud naming of everyday objects and every object in sight of Fiona, singing and humming her favorite songs. Frequent drawing attention of Fiona was on the clock, the time and reading the common hour and daily reading and analyzing the calendar. Helpful, according to Fuller<sup>5</sup>, also supposed to be common commenting weather outside the window and watching the reminiscence exercise with photographs, talks about family and remembrance. Fuller<sup>5</sup> recommended besides further comprises repeating strings of words, ex. days of the week, counted names of months, prayers, poems and a common view and discussions of colorful newspapers. Making shopping lists and learning it before and while shopping, Roksana set with Fred duration and frequency of meetings with Fiona. Meetings were held at least 2 times a week for 60 minutes (with a break for tea after the first hour of work). Roksana received from Fred workbook for patients with AD in which Fiona previously worked with him and photocopy of diagnosis prepared by neuro-speech-therapist.

At first, Fred was in constant e-mail contact with me, because sometimes needed a consultation. He asked and discussed with me for ex. if one person working with his wife enough, or perhaps it would be necessary to hire speech therapist as additional supporter? He wanted to ensure the very best quality of care for his wife. With time, Roksana became a leading expert supporting his wife. With the obtained diagnostic documents Roksana has planned her own workshop. She came to me for a few FTF consultations, sharing ideas. I suggested a couple of books. Roksana did not have the experiences to date in support of AD patients but fortunately while the third year of her Bachelor studies in Special Education, she attended course pursued by me- "Habilitation of Adults with Intellectual Disabilities", including a content and literature on the issues of AD.

The first few meetings with Fred and Fiona Roksana devoted to an orientation regarding the potential of Fiona's functioning. Roksana wrote in the field notes: "several meetings were enough to convince that support never goes according to a predetermined plan. In fact, depending on the time of day, weather permitting, from being both Mrs. Fiona and me (yes, the supporter also may have a weaker

day) were placed in a better and worse days". Fiona's husband, Fred, was not a passive participant of the support. He showed Roksana from the beginning interest in the progress of his wife and repeatedly suggested place the accent on one type of task, ex. exercise on the clock, the money, the repetition of names of family members. Fred initially stayed at home during meetings conducted by Roksana. Together with Fiona and Roksana he drank a cup of tea during a break in exercises. According to Roksana, her commitment had a very positive impact on the cooperation and support, which lasted from November 2010 - the end of May 2013.

**Beginnings of the Support of Fiona with AD:** The starting point for the planning of educational support by Roksana was based on discussions with family members and participant of support. All documents were provided by the family members and among them, formal and informal documents such as previous exercises carried out by Fiona with AD. Planning cognitive-educational support for Fiona was, according to Roksana, difficult process. All kinds of outlines, guidelines, or other types of plans and scenarios in her opinion, were mainly just a sketch to support activities that required the flexibility of a supporter. Roksana wrote in the field notes: "I myself, after a year of working with Mrs. Fiona stopped these plans stack and chose my tasks during the meetings. Because from the entrance to the home of Fiedler's family I knew, if today Mrs. Fiona feels better, or may be she has one of her worst days". Roksana continued in the notes "what is the challenge in this support is the flexibility in the implementation of contingency plans.

Therefore, it is important to continuously expand the support that if ex. Mrs. Fiona was unwell, Roksana have had a different type of task to propose. Roksana believed that well prepared therapist and supporter is one who has prepared a set of exercises both of these better and these inferior days. Roksana while supporting Fiona noticed that "for the first hour Mrs. Fiona performed her tasks efficiently and in the second hour she was normally abrupt, got slowdown and expressed difficulties in previously not difficult tasks. Roksana wrote in the notes "in a situation where I could see that Mrs. Fiona cannot cope with any proposed task, I resisted the troubling exercises while meeting and offered manual work as puzzle, matching shapes, connecting points. From time to time I tried to turn any difficult task and usually applied this effect. Most importantly, would not stick rigidly pre-determined scheme."

Roksana also wrote "of course there is always the possibility of an appeal on a given day of joint activities or their gear. However, in working with Fiona with AD, caregiver and support person quickly can see that these so called weaker days happen relatively often. So I never gave up the meetings with Mrs. Fiona, if the cause of the weakening of her intellectual abilities were not actual

health problems (fever, headache, physical pain etc.)".

**Problems constantly occurring during the implementations of tasks by Fiona with AD:** Based on own experience and 30 months of support, Roksana indicated that problems can occur in almost any proposed task. Fiona had difficulty while concentrating and often forgot what she wanted to do. Fiona easily got nervous in a situation, inability to execute a command, or when she was corrected, as manifested by the words: "I cannot", "I cannot today," "this is stupid" and even by knocking on the table and speaking obscenities. It happened so often that Fiona did not understand the command of Roksana and had problems with starting the job. Roksana often started solving the problem instead of Fiona, so Fiona could see how to perform the task. As person with AD, gestures were more understandable for Fiona than words because words were gradually becoming more and more incomprehensible.

Another recurring problem during the implementation of the exercises was associated in particular with Fiona's behavior when she ignored Roksana and tried to do the job "on her way". In the time of working with Fiona, Roksana supplemented field notes illustrating the ongoing and common problems with the proper performance Fiona manifested.

### **Cognitive - educational support of Fiona with AD**

Selected techniques and tasks performed by Fiona have been grouped by Roksana in the following themes: consolidating and expanding vocabulary, orientation in time and identical elements combination in pairs. These themes were developed by Roksana based on the indications and diagnosis of neuro-speech-therapist Fay Fuller<sup>5</sup> and the literature provided by authors such as Cieszynska<sup>3</sup>, Gabriel<sup>6,7</sup>, Danaher<sup>4</sup>, Zmudznska<sup>17</sup> and Ratajczak et al<sup>16</sup>. We describe below each thematic group of led support which includes the following description: materials used, variants of the task, goals, problems occurring during Fiona's support.

**Materials:** To complete the task supporting person prepare as Roksana did, the teaching aids, mostly by him/herself. The publishing market in current Poland is rich and has a wide range of publications that describe the theoretical and clinical aspects of Alzheimer's disease. Publications of sample tasks for implementation with someone with AD or a teaching aids designed to work with people with AD, are unfortunately not many on the Polish market. Therefore Roksana by herself performed aids that supported the cognitive-developmental functioning of Fiona. She mainly based on the textbooks on aphasia, Alzheimer's disease and methodological volumes indicated in the bibliography of the text. Selected photographs of such aids are included in this article.

**Variants of the task:** Depending on the capabilities of current intellectual disposal of Fiona, Roksana proposed easier or more difficult task version. During one meeting, cognitive exercises were alternated with other tasks and implemented as several variants of the task of the same thematic group. When Fiona has not coped with the task, or its' variant, Roksana interrupted task and started either another variant or to another task. The objectives of the exercises indicated and determined by Roksana had covered cognitive sphere and focused attention of Fiona with AD. To perform a single task Roksana gave Fiona 20 minutes or even sometimes 30 minutes. It can be seen that while the best state of functioning, Fiona could achieve up to four tasks within one meeting, lasting 120 minutes in total. As Roksana underlined in the field notes, she was much depended on the current disposal of Fiona and progress of her disease.

**Occurring problems:** Supporting Fiona was for Roksana confrontation with the truth that with the passage of time and continued support of Fiona, problems will occur while the tasks. As she stressed, this is a natural process and one should not be discouraged. She ran to keep field notes where she wrote about experiencing all the types of problems encountered and worked out. Roksana wrote also further suggestions of how to work with Fiona in the event of problems. What we can see the main problems were associated with the implementation of tasks by Fiona, sometimes connected with the need to modify them and do not give up the exercises at all. Roksana entered in the notes also guidance for support person based on her own participatory observation facing in the field problem situations.

**Techniques of cognitive-educational support of Fiona with AD:** The following exercises were limited to discuss only 3 groups of exercises as: expanding and fixation of vocabulary, orientation in time, a puzzle - matching elements in pairs. They are not all types of implemented activities because Roksana used also math elements and the numerical material as well as other activities such as walking and talking with Fiona and oral exercises by walking along a nearby city park in Torun.

### **Fusing / expanding vocabulary**

**Materials:** A variety of illustrations (which have been cut from magazines) and cardboard with captions to illustrations were taken. They can be grouped by category e. g. fruits, animals, actions, colors, illustrations/blocks of different shapes (ex. geometric figures, star, sun, heart etc.). Multi-colored cardboard were taken to perpetuate the names of colors and/or animals, which instead of mesh or numbers has a different color on each side. Syllabic domino, sticky opposing adjectives and illustrations were used to perpetuate the names of body parts.

**Variants of the task:** Roksana pulled in front of Fiona cardboard boxes with illustrations. Fiona corresponds to

what she sees and/or adjusts the cardboard box to the right signature.

Roksana puts before Fiona syllabic domino. Fiona's task consists in laying the bricks of domino and design correct words. Roksana puts before Fiona on one side a group of adjectives. On the other side puts a cardboard box with a single adjective. Fiona's task is to find the adjective which appears on a single carton, lined, opposite adjective of the next group of adjectives (ex. bright - dark, healthy - sick).

Roksana puts before Fiona colorful cardboards and mixed color names. The task is to pair the color name on the carton and a given color. Roksana puts before Fiona colorful cartons and asks to select a specific color, saying to Fiona for example. "Please, show me the color red". Roksana indicates a single cardboard box and asks for the name of the specified color.

Roksana throws the dice with colors and Fiona has the task to name the color that came out. Roksana shows various objects from the environment and asks that Fiona said and/or wrote down what it is and such. What color is the object? What is it like?

Roksana asks for the names of family members e.g. on the basis of the watched photos and Fiona responds and writes them on the sheet. This task also practiced Roksana for exercising Fiona's legible handwritten signature. Roksana puts before Fiona illustrations e.g. silhouette of a female and a male, body parts as face etc. and asks that Fiona named indicated parts of the body. Then Roksana asked Fiona to name body parts shown on her and then encouraged Fiona to name parts of her body.

**Purpose:** The aim of the exercise was: consolidation/expansion of vocabulary of Fiona, focus on her potential to facilitate communication with physician while visits. In addition, consolidation of clear written signature, recording names of family members, practicing reading and writing skills, practicing concentration and practicing eye-hand coordination were essential.

#### Observation of Fiona - occurring problems:

- Fiona incorrectly matches the signature of the illustrations,
- Fiona cannot call and / or write the specified object /shape/color/body parts,
- Fiona mostly confuses color red to blue and vice versa,
- Fiona has a problem with a legible signature,
- Fiona forgets the names of family members.

#### Tips for a support person:

- Roksana believes that emphasis should be placed on the

names of objects/places of the ward environment, names of family members of Fiona, her handwritten signature and name of body parts.

- While the task of syllabic domino Roksana indicated Fiona first syllable and if she still had problems with the submission of words, read in conjunction with all the possibilities and Fiona pointed out the possibility creating the correct word (the number of blocks to knock Roksana adapted to the current disposal of Fiona).



Photo1: Fusing and enrichment of vocabulary

#### Orientation in time

**Materials:** Cardboard boxes with the names of days and months, Analogue clock, Cartons of clock pointer indicating the specific time with signatures, Calendar (preferably used every day).

**Variants of the task:** Roksana breaks against charges of cardboard boxes with names of days of the week / month. Fiona puts cardboard in the correct order. To facilitate Roksana began indicating Monday/January.

Roksana presents the board with numbered names of the week/month. In addition, Fiona receives a card with the names of days, of the week /months recorded in random order. Fiona's task is to locate the on board indicating piece of the week/ month and save attributable to the order number, ex. Monday - 1; Thursday - 4, December - 12 etc. Roksana puts before Fiona calendar (or comes up with Fiona to the calendar hung ex. on the wall) and helps her to read today's date, day of week, month and year. This task is best done after the previous two versions. Roksana puts before Fiona cartons, showing the clock pointers indicating a specific time and captions to them. Fiona's task is to pair cards with the names of the clock to the correct time. Roksana shows Fiona on the clock-needle different hours. Fiona reads the time from the clock.



**Purpose:** The aim of the exercise was to improve orientation in time by Fiona, fixation using a calendar, an exercise of reading time on a clock-needle, practicing reading, fixation of reading and writing numbers (range 1-24), eye-hand coordination, attention.

**Observation of Fiona - occurring problems:**

- When exercising the names of specific days of the week and months, sometimes Fiona did not understand the command, did not know how to begin the task
- Fiona had problems with reading the names of days of the week/month and hours (both reading hours of the clock and captions to illustrations)
- Problems with reading the indicating hour clock often resulted from an incorrect reading of the numbers on the clock by Fiona
- Fiona had problems with placing them in the correct order of names of days of the week/month
- Fiona could not find (or indicated wrongly) the specified day of the week/month on the board
- Fiona had problems with the calendar, for example. She felt overwhelmed trying to identify the items on the calendar, she did not know what to look for, did not know what the individual elements.

**Tips for a support person:**

- The font and its thickness in learning materials was adapted to the possibilities of Fiona
- Before asking Fiona for hands of the clock, worth reading practice concerned the digits of the clock because cause of abnormal readability was often associated with misread digits/ numbers of the clock
- In a situation where Fiona could not start the task of arranging the order of days of the week or month, Roksana pointed to the first day of the week/month.

**Connect a pair of identical elements**

**Materials:** Charter of the memo e.g. repeated twice with different illustrations (the illustrations can be signed), Board with the shapes and the same shapes in the form of loose items/blocks,

**Variants of the task:**

**Memo:** Roksana puts before Fiona, for example, 8 cards, of which 4 are repeated twice. Roksana says / reads what is on the illustration and Fiona after her repeats, repeats. Roksana turns all the pictures face down and reveals one card and says what is on the illustration. Then Fiona again turns the card reverse and discovers another. When Fiona goes to the illustration that already bore on one of the earlier face-up cards, Roksana tries to help her remember

where this previous card is located. The task is to combine pairs of all the illustrations.

**Shapes:** Roksana puts before Fiona the board with shapes (ex. a circle, square, triangle, heart, star) and the next scatters the same shapes in the form of loose items/blocks. Fiona's task is to match the shapes from the board with scattered shapes. With each shape Roksana repeated aloud with Fiona name of the shape. Each shape can be marked with a different color and can be used in the same task to repeat the names of colors.

**Purpose:** The aim of the exercise was to broaden and consolidate the vocabulary of Fiona, repeating the names of shapes, colors, improving eye-hand coordination, improving memory, concentration, attention, task execution and relaxation.

**Observation of Fiona - occurring problems:**

**Memo:**

- Fiona could not tell what is in the picture,
- She could not read the caption under the illustration,
- Fiona turned away several cards at once,
- Fiona was not able to connect the illustrations in pairs.

**Shapes:**

- Fiona named wrong shapes and colors,
- She could not find the same shape,
- Found the correct shape but placed it in the wrong area on the board,
- Fiona looked for the correct shape of already stacked on the board.

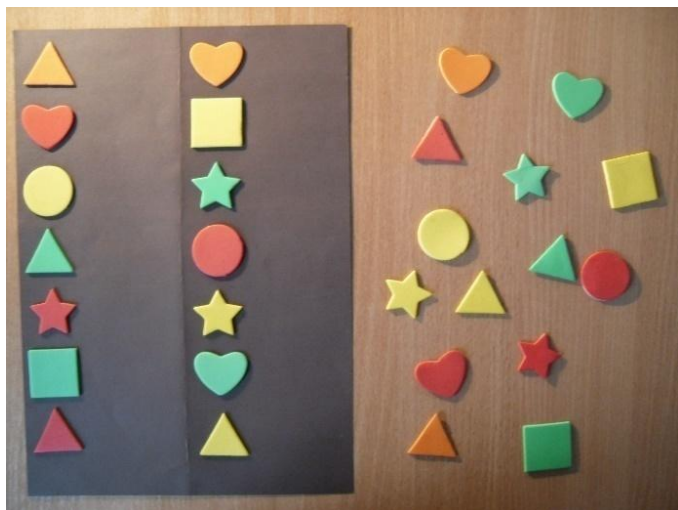
**Tips for a support person:**

**Memo:**

- Roksana used in tasks illustrations of items that occur in the environment of Fiona
- Number of illustrations presented to Fiona was adapted to her current capabilities.

**Shapes:**

- To perform these task available materials Roksana applied, among others, in stationery stores, foam parts that had adhesive on the back, so easy to stick them on the board and perform their function well as loose components.
- In a situation where Fiona had trouble finding the same shape - Roksana indicated its proper shape in scattered parts.



**Photo 2: Memo**

**Support Analysis:** After 30 months of experience supporting Fiona, Rokksana still believes that the most important conclusion dawn while working with Fiona and her husband Fred, was the right to revealing weaknesses and limitations, referring to Fiona, her family, but also Rokksana herself. Rokksana believes that starting working with Fiona, while being undergraduate student writing the thesis in the study of Special Education on the competence of special educators and therapists helped her to verify in practice the theoretical recommendations of home-based support for persons with AD. After experiencing the 30 months meetings and support of Fiona, Rokksana is of opinion that appearing in the academic literature postulates, concerning the desirable characteristics and competencies of special educators, caregivers supporting people with AD and disabilities, seem to be overly idealistic. They rather are describing the super heroes than people having the right to being helpless or weak facing the troubles while support or care.

Therefore Rokksana after experiencing 30 months of support for female with AD understands the supporters who are affected by the state of burnout. According to Rokksana, special educators, caregivers, teachers everywhere meet with criticism of their work, with claims on how their work should look like. Rokksana wrote in notes "people expect that those professionals whose work is based on the support of others will live with the mission, giving up themselves." Rokksana, after 30 months of support for Fiona, believes that people working in the areas of support, are aware of the degree requirements and professional challenges. Supporting person with AD, according to Rokksana requires above all patience, which is much difficult to get, when caregiver had a bad day, had a headache, or just that day feels bad.

Rokksana wrote in the notes "when I felt tired and I saw that Mrs. Fiona is also at the end forces, for the good of both of us I chose easier tasks." Performing easier exercises was provided at the time of physical and mental fatigue of both

partners of interactions: Fiona and Rokksana. Rokksana justified her choices that support during the state of fatigue caused that any kind of failure awaked the slightest frustration and Fiona's anger. Rokksana emphasizes that Fiona from the beginning to support, this means from the end of November 2010 had troubles with understanding the words that Rokksana headed to her, so Rokksana had to rely on gestures and facial expression. She tried very much to be with her gestures and facial expressions.

Rokksana believes that cognitive-educational support for Fiona and cooperation with her husband Fred are the most valuable experiences of volunteering and the work undertaken during the study. She is of opinion that just by Fiona's support, she learned an individual approach to people with disabilities as a result of AD. In addition, Rokksana learned how to create own workshop, flexibility in the implementation of any plan and above all, patience and responsibility. The theory gained in college was the starting point for her to work with Fiona. Rokksana believes that the support of Fiona has equipped her with valuable experience and skills and revealed bright and dark sides of the cognitive-educational support to person with AD. The dark side perceived by Rokksana while the support for Fiona is clearly recognized as subjectively perceived helplessness and lack of advancement by Fiona in a confrontation with progression of the disease.

## Results

Results of participant observation of home-based, individual cognitive-educational support of female with AD, illustrate educational work and efforts to continuous improvement of cognitive functioning. The study does not indicate at any time the symptoms of cognitive improvement of Fiona but only the cognitive streamlining in the context of constant progress of the disease.

A positive aspect of individual support based on the family home and conducted in the family ground, provides a sense of security to the person with AD, associated with some degree of recognition of symbols in the close environment. In the case of Fiona, who endured a very bad start being placed in the living center support, solution of the individual home-based support, offered by volunteer (initially), then a professional special educator Rokksana, have become a proper alternative for group support activities which Fiona endured very bad. Individual support referenced cognitive learning at home, could also be a comfort to her husband Fred and reduced his burdens a bit and congestions associated with progression of the illness of his wife.

Rokksana while leading the support had come face to face with the state of her own helplessness. She felt also powerless in the face of lack of own greater achievements as the supporting person and of loss of cognitive abilities and progressive disease in Fiona. She felt also slightly embarrassed while changes in behavior of Fiona e.g. while

emerging obscurities. Roksana gently mentioned of her own weakness in the field notes and shows understanding for those who support persons with Alzheimer's disease. She understands presently burnout grounds as related to incessant claims of the environment and the requirements of total dedication and devotion from supporting persons.

### Discussion

Fiona's cognitive-educational support provided from the end of November 2010 until the end of May 2013 by Roksana, illustrated support in a family and home-based environment of Fiona. Fiona was not exposed during 30 months of support and progress of the disease, to radical changes in her environment, related to the placement and adaptation to the day or stationary living center. She was not exposed to the feeling of anxiety, irritability, discomfort and tensions in dealing with other persons diagnosed with AD being in different stages of disease. Roksana received regular feedback from both: Fiona and Fred, that she is a person very well liked and accepted by both. Fred often said to Roksana that Fiona is waiting for her, waiting for her visits and common activities.

Educational support affected the quality of everyday life of husband of Fiona who providing constant support for his wife also had more moments for relaxation and free time for himself. He also had a sense of well-implemented support at home, I could see it from the time when Roksana became a trusted person which Fred could calmly entrust the care and support of his wife. AD is a progressive disease; it cannot be stopped in a medical or therapeutic treatment. Cognitive-educational support streamlined only current cognitive functioning of Fiona and required current adjustment, flexibility, support and activities to sustain the skills of Fiona and her current disposal as well as her changing mood. Much depended also in my opinion on the support person, her ingenuity, creativity and understanding of the process of being ill with Alzheimer's disease.

In my opinion, progress of the disease and current dispositions of Fiona required creativity and flexibility from Roksana. It required also the skills of the peaceful response to the problems and difficulties of Fiona while her protest in situations of helplessness. Not without significance is accepted and complete devotion based attitude to the disease of wife expressed by Fred who according to Roksana "on the part of Mr. Fred I felt needed. He definitely is a very sincere person and always spoke openly about his expectations and perceptions. And even when I had moments of doubt in the sense of therapy and support, he got me with this doubt rerouted to their positive insights. For example, he boasted to me that Mrs. Fiona in her free time takes out some teaching material and started practicing, or they repeated something together.

In the above text were included cognitive-educational techniques and their only selected topics related to vocabulary, orientation in time and matching elements in

pairs. Cognitive-educational, home-based support is implemented in Poland by volunteers, special educators, occupational therapists, social workers and family members of people with disabilities in the field of intellectual and cognitive problems including AD. It is helpful in improving the quality of everyday life of people with cognitive disabilities and their families providing emotional relief and a bit of free time. Situation of overloading of support persons caused by the excessive and unrealistic expectations of the families should also be taken into account. Roksana mentioned in her field notes about evolving attitude of Fiona's husband who from the initial hope of halting the disease progress through cognitive-educational support, has gradually approved more realistic goals as strengthening and improving the quality of life of his wife.

### Conclusion

The case study of cognitive-educational support for female with AD is a condensed illustration of the 30-month support, the chosen techniques and problems that occur with the person being supported. The study was not designed to evaluate and assess the impact of cognitive-educational support to the functioning of the state of a woman with AD but included the descriptions of individually grounded, cognitive-educational support, based at home. In addition paper contains the illustrated overview of the key and selected techniques of support. We hope that this paper will inspire the debate over the value of individual support at home for people with AD, conducted by volunteers, students of special education, special educators, occupational therapists and social workers.

The success of a support may also be perceived taking into account the period of time that Roksana supported Fiona, that is 30 months and that she was accepted by both Fiona and her husband Fred. Recently after a year break in the support by Roksana, from June 2014, Fiona is exercising with another person, also a graduate of Special Education at FES at NCU. The cognitive-educational support meetings' time was limited to 1.5 hours during the week, due to illness progress in Fiona.

How important is implemented individually cognitive-educational support for Fiona in the opinion of Roksana? Roksana wrote "I believe that cognitive-educational support is valuable. Even if at some point ceases to produce the expected results in the sphere of intellectual performance, it is important for the family itself to be aware of someone who supports their efforts. The more AD occurs in the elderly people, they are often left to fend for themselves. So this is something fruitful for both sides: for a person with the disease, where support helps to promote and practice intellectual functions as long as possible and also provides emotional support, as a sense of security and friendliness. For the family members such meant support is a relief, the possibility to manage personal affairs during the time of treatment. Finally for the support person - a

special educator, such meetings are valuable experience and the ability to shape personality features such as responsibility, orderliness, empathy and recognizing the importance of implemented support".

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