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# Training for Peer Support Workers in dementia field

Project Result 1 Develop, create and design training materials and methodologies



## Index

Intro	duction	4
Meth	odology	4
Natio	onal context analysis	5
1.	Norway	5
2.	Greece	6
3.	Italy	6
4.	Romania	8
Train	ing material	8
1.	Norway	8
2.	Greece	9
3.	Italy	.10
4.	Romania	.11
Train	ing courses piloting	13
1.	Implementation	.13
2.	Participants' evaluation	.14
Facil	itators' evaluation	15
Cond	lusions	18
<b>Conc</b> 1.	Areas of improvement/unaddressed needs	
		.19
1. 2.	Areas of improvement/unaddressed needs	.19 .20
1. 2.	Areas of improvement/unaddressed needs	.19 .20 <b>21</b>
1. 2. <b>ANN</b>	Areas of improvement/unaddressed needs Closing remarks EX 1 - Training course piloting in Norway	.19 .20 <b>21</b> .21
1. 2. <b>ANN</b> 1. 2.	Areas of improvement/unaddressed needs Closing remarks EX 1 - Training course piloting in Norway Training evaluation	.19 .20 <b>21</b> .21 .22
1. 2. <b>ANN</b> 1. 2.	Areas of improvement/unaddressed needs Closing remarks EX 1 - Training course piloting in Norway Training evaluation Conclusion	.19 .20 <b>21</b> .21 .22 <b>24</b>
1. 2. <b>ANN</b> 1. 2. <b>ANN</b>	Areas of improvement/unaddressed needs Closing remarks EX 1 - Training course piloting in Norway Training evaluation Conclusion EX 2 - Training course piloting in Greece	.19 .20 <b>21</b> .21 .22 <b>24</b> .24
1. 2. <b>ANN</b> 1. 2. <b>ANN</b> 1. 2.	Areas of improvement/unaddressed needs Closing remarks EX 1 - Training course piloting in Norway Training evaluation Conclusion EX 2 - Training course piloting in Greece Training evaluation	.19 .20 <b>21</b> .21 .22 <b>24</b> .24 .25
1. 2. <b>ANN</b> 1. 2. <b>ANN</b> 1. 2.	Areas of improvement/unaddressed needs Closing remarks EX 1 - Training course piloting in Norway Training evaluation Conclusion EX 2 - Training course piloting in Greece Training evaluation Conclusions	.19 .20 <b>21</b> .21 .22 <b>24</b> .24 .25 <b>27</b>
1. 2. 1. 2. ANN 1. 2. 2. ANN	Areas of improvement/unaddressed needs Closing remarks EX 1 - Training course piloting in Norway Training evaluation Conclusion EX 2 - Training course piloting in Greece Training evaluation Conclusions EX 3 - Training course piloting in Italy	.19 .20 <b>21</b> .22 <b>24</b> .24 .25 <b>27</b> .28
1. 2. <b>ANN</b> 1. 2. <b>ANN</b> 1. 2. <b>ANN</b> 1.	Areas of improvement/unaddressed needs Closing remarks EX 1 - Training course piloting in Norway Training evaluation Conclusion EX 2 - Training course piloting in Greece Training evaluation Conclusions EX 3 - Training course piloting in Italy Participants to the piloting	.19 .20 <b>21</b> .21 .22 <b>24</b> .25 <b>27</b> .28 .28
1. 2. <b>ANN</b> 1. 2. <b>ANN</b> 1. 2. <b>ANN</b> 1. 2. 3.	Areas of improvement/unaddressed needs Closing remarks EX 1 - Training course piloting in Norway Training evaluation Conclusion EX 2 - Training course piloting in Greece Training evaluation Conclusions EX 3 - Training course piloting in Italy Participants to the piloting Evaluation of the piloting	.19 .20 <b>21</b> .21 .22 <b>24</b> .25 <b>27</b> .28 .28 .29
1. 2. <b>ANN</b> 1. 2. <b>ANN</b> 1. 2. <b>ANN</b> 1. 2. 3.	Areas of improvement/unaddressed needs	.19 .20 <b>21</b> .21 .22 <b>24</b> .24 .25 <b>27</b> .28 .28 .29 <b>31</b>



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ANN	EX 5	- Training course piloting in Romania (Bucharest)	39
3.	Cor	clusions	37
	2.2	Part 2. Improvements	36
	2.1	Part 1. Satisfaction	34





## Introduction

The Training for Peer Support Workers (PSW) in dementia field is an innovative training course which aims at equipping peer support workers with essential skills in order to be active in supporting people with dementia, informal carers and even professionals in this area. The training content includes knowledge on dementia, symptoms, causes, and how it affects the individual in daily life, communication techniques, while there is also a focus on autonomy and meeting the needs of people with dementia on their own premises. This document gives an insight on the methodology used to develop the curriculum, the training material and also on the national context analysis in each of the partner countries and on the piloting of the training program in each of the partner countries of the PIA project, meaning: Norway, Italy, Romania and Greece. The present report also offers a description of the results of the testing of the training materials in the partner countries.

## Methodology

The course was based on extensive research in national dementia plans of the participating project partners, for those countries which have completed national dementia plans, whereas need analysis was also implemented to clarify the triggering motivational factors of being a PSW. Literature review was also applied to enrich the PIA project material with current knowledge from countries as well as research groups who have worked with PSW. Moreover, Dementia Friends material created from Alzheimer's Society, UK was used to deliver the message of Dementia Friendly communities in current and future PSW across the participating countries of the PIA project.

Learners will have access to the training material either via their active participation in training awareness seminars, or activities in the platform, in which they can interact one another, exchange possible experiences given by their lived experience with people living with dementia. The delivery methods will include powerpoint presentations, videos, auditory documents, chat, open discussions in the forum and group discussion via the PIA platform. Moreover, the training material will also include role playing activities as well as raising empathy techniques in which future PSW will have the opportunity to interact effectively with dementia caregivers, dementia care services and mainly with people living with dementia:

The training material course will entail four different modules with different aims and contents each. **Module 1** encompasses general information about dementia for the public which aims at providing crucial options about risk and protective factors, prevalence, dementia services, early symptoms etc. **Module 2** constitutes the Dementia Friends program which raises the issue of making dementia friendly communities, including 5 key





messages about dementia and one dementia friendly action. Module 3 describes the role of PSW in dementia care providing the basic characteristics which PSW should have and **Module 4** includes dementia services which exist in each country-partner of the PIA project as well as a series of psychotherapeutic techniques on how to provide empathy and have successful contact with people living with dementia, e.g role playing, empathy techniques, experiential exercises, and communication skills.

## National context analysis

#### 1. Norway

In Norway, there are good estimates of the prevalence of dementia in nursing homes and among people receiving home care. Just over 80 per cent of those who have long-term care in nursing homes have dementia, and over 40 per cent of those aged over 70 who receive home care have dementia. By combining these figures, it is estimated that there are approximately 71,000 people with dementia among home care recipients and nursing home residents. In addition, there are those who do not receive home services or are in a nursing home.

The rise in life expectancy in Norway will more than double the number of people with dementia from 2015 to 2050. This is based on calculations that have estimated a doubled incidence in Western Europe during the same period (ADI, 2015). Worldwide, the number of people with dementia is estimated to triple or quadruple from 2015 to 2050.

These projections are worst-case scenarios. However, results from several studies show that over the past 20 years there has been some improvement in cognitive function among the elderly (Llewellyn, 2009; Christensen, 2013) and reduced risk of dementia (Matthews, 2013; Prince, 2016).

Increased educational levels, improved lifestyle habits, such as reduced smoking and healthier diets, plus better control of risk factors for cardiovascular disease, such as blood pressure treatment, may have helped reduce the risk.

Nevertheless, there is little change in the proportions within different age groups that have dementia. The most likely explanation for the increased prevalence of dementia in the total population is increased life expectancy in general and more elderly people, plus that people with dementia are living longer with the disease.

Our vision is to develop a more age-friendly society. Therefor services must be developed where the elderly can contribute on their own terms and based on what they believe is important and meaningful to them (Johansen 2013). Experience from work with recovery





as a treatment philosophy means that the individual must have more influence and control over the services provided to them and be involved in deciding what works (Johansen & Løken 2019).

In Norway, peer support workers are widely used in substance abuse services, mental health work, NAV and child welfare. Some of these positions are funded by government grants. This grant scheme facilitates a more systematic capacity building than previously. KBT vocational College believes that the use of peer support workers in substance abuse services, mental health work, NAV and child welfare has a transfer value to dementia care. We need to find a blueprint-model for integrating peer support workers into the existing healthcare services. We hope to achieve this via the PIA-project with our partners I Greece, Romania and Italy. This intellectual output will enable peer support workers to transform their tacit knowledge to a form of explicit knowledge that can help others in a similar situation.

#### 2. Greece

Dementia services in Greece are largely expanding; however, big needs as well as various places across the province which have limited access in dementia care demand reinforced solutions. PSW can be an inseparable part of the dementia care team, because due to the fact that they are experts of their own experience, their perspective along with lived experience about care can definitely facilitate dementia services and boost the already existing efforts.

By means of the aforementioned frame, Greek partners created a training material including the steppingstones of including PSW in dementia field:

Providing recent data about dementia (e.g., risk factors, early symptoms, dementia friends program etc)

Defining and explaining the role of PSW- providing the main characteristics/barriers/motivations about why to be a PSW

Describing dementia services in Greece-ways to held as a PSW- building together a humanistic model for PSW when helping people living with dementia-facing dementia challenges in Greece

Delivering reflective exercises in order to relive their experience and boost feelings of empathy, compassion and support

#### 3. Italy

In Italy a peer-support worker cannot be employed *as such* in the care sector. He/she would have to comply to the other regulations for care workers, meaning that:





- He/she will have to have a VET qualification as social-health care support worker (OSS) to be employed in formal services such as residential care, day care or home-care services
- He / she won't need any formal qualification to be employed as domestic care worker by individuals (older persons or someone from his/her household)

Because of this, we don't consider it useful in the Italian context to provide dedicated VET training for peer-support workers.

On the other hand, in Emilia Romagna region we have several programmes employing PSW as volunteers in the following sectors:

- Mental health
- Disability (including carers of people with disabilities)
- Dementia (informal carers)

In the mental health field, where experiences are more developed, there have been training for PSWs providing the formal VET qualification of "quidance counsellor" after 200h of formal training.

Contents: management of the help relationship, analysis of user needs and requirements, management and enhancement of user resources, management of active interviews (effective communication, active listening, assertiveness), motivational approach in the contests that support change, user support for a better perception of themselves and their pathology, support for the user in making decisions and autonomous resolution of problems, as well as privacy management.

In connection with the findings of the research and the analysis of the Italian context, it emerged that a Peer Support Worker figure in the field of dementia would still be very useful. In the Italian context, it was decided that such a figure could be addressed to caregivers of persons with dementia, so that they could use their experience to provide other caregivers with their own experience. It was pointed out that personal story and spontaneously acquired skills in caring for a loved one with dementia are crucial in order to offer suggestions for improving the lives of carers and people with dementia.

To this end, the training course for people with experience in caring for people with dementia that was developed and tested in Italy focused on acquiring and strengthening knowledge and skills to promote peer exchange and support on the one hand and community awareness on the other. The training also had a strong practical imprint, which enabled the participants to consolidate theoretical assumptions and to make their own experience the object of learning.

The final objectives were to create a figure capable of:





- Welcoming informal carers and providing basic information when accessing services
- Peer-support / mentoring / be-friending
- Motivation / empowerment / self-management
- Contributing to policy making and training with an advisory role

#### 4. Romania

In Romania just a few attempts were made, within different projects, to outline the theoretical frame of the Peer Support Worker. However, the term is novel for our society and not very well understood. It is not yet acknowledged as a potential occupation and there is not a lot of information of how such a person could be integrated in the field of social/medical care. There are no national strategies or policies regarding the interventions post-diagnostic of Peer Support Workers for the people with dementia and their families.

While other countries are defining and refining the role of the Peer Support Worker in dementia, in Romania we are still at the beginning of the process.

However, the importance of such a support is paramount as it was proven to reduce loneliness associated with the diagnosis of dementia, helping people to live and cope with.

## **Training material**

Material was initially developed in English in order to be free and available in the PIA platform for the public and is available for free download at this link. The training material has been then translated and adapted to the national context of each project partner, according to the needs, priorities and dementia services of each country. In the text provided below, national adaptations of the originally created material are presented so as the reader can identify cross cultural differences and needs existing between Norway, Italy, Romania and Greece.

#### 1. Norway

The training course in Norway was conducted as an 8-hour session with 8 participants from 2 municipalities (4 peer support workers, 2 managers from homecare, 2 members of the memory team). The training course consisted of three modules: a theoretical module, a practical module and a reflection module.

Module 1:





Introduction to dementia - definition and prevalence

Learning outcomes: Introduction to Dementia, Dementia prevalence, Risk factors for Dementia, Dementia symptoms, Different types of Dementia, Progression of Dementia-Different stages.

Module 2:

Practical exercises designed to give participants insight into how the symptoms affect activity in daily life.

Learning outcomes: The participants get to experience for themselves how chaotic and frustrating everyday life can be for a person with dementia, which will lead to increased insight and empathy.

Module 3: Reflection on the role of the peer support worker

Learning outcomes: Understand one's own motivation and how their lived experience can be used to help persons with dementia and their families.

The material in Norwegian language is available for free download at this link.

#### 2. Greece

According to the previous content categories, we delivered an 8 hours training program which included 4 modules based on the current needs of dementia services in Greece as well as the way PSW should be aware of before thinking of their role in the future of dementia care. During the duration of the material implementation, we focused on motivating them to be care members in order to trigger feelings of empathy, humanity and support provision as part of their previous experience as caregivers.

Module 1: Introduction on dementia - general definition and prevalence

Learning outcomes: Introduction to Dementia, Dementia prevalence, Risk factors to Dementia, Dementia early symptoms, Different types of Dementia, Progression to Dementia- Different stages

Module 2: Dementia friends program- Why a PSW is a dementia friend- How can deliver the message of dementia friendly communities

Learning outcomes: Introduction in Dementia Friends program, 5 key messages about Dementia Friends program, Activities concerning Dementia Friends

Module 3: The role of PSW in dementia care





Learning outcomes: Peer Support Workers' characteristics, Roles, Characteristics, Why become a PSW, Countries specific issues

Module 4: Dementia Services in Greece-Significant issues for people living with dementia e.g. legal pending issues, human rights, and practical activities (reflective techniques, active listening, role playing)

Learning outcomes: Dementia Services in Greece, What dementia friendly communities mean, Significant issues (human rights, economic issues, communication techniques, exercises)

The material in Greek language is available for free download at this link.

#### 3. **Italy**

A 16-hour programme divided into 5 modules was developed in the Italian context to meet the identified needs. The final objective of the programme is to create a profile of caregivers able to use their experience through processing, communication and support skills.

Module 1: Introduction on dementia and personal experiences

Learning outcomes:

- To be clear about how dementia can impact on the person with dementia, their life and relationship with family members and carers
- Being aware of the consequences of stress and burnout •

Module 2: The role of the Peer Support Worker (PSW)

Learning outcomes:

- To know the figure of the PSW in general and in the Italian context and in the context of dementia care
- Being clear about the benefits of the PSW figure for caregivers and community awareness

Module 3: Initiatives and contexts

Learning outcomes:

 Being aware of the contexts in which an Expert by Experience can operate and what actions he/she can perform

Module 4: Skills and strategies

Learning outcomes:





Knowing how to approach, communicate and help a career of a person with dementia

Module 5: Stories of Peer Support Workers

Learning outcomes:

- Being able to raise awareness and support through storytelling and experience
- Knowing how to communicate with a carer and with decision-makers for change and awareness-raising

The material in Italian language is available for free download at this link.

#### 4. Romania

#### Asociatia Afect (lasi):

Each meeting comprised a Power Point presentation prepared by the Greek Association of Alzheimer's Disease and Related Disorder - Alzheimer Hellas from Thessaloniki, our partners in the project.

The sessions were supplemented with a series of printed documents such as "World Alzheimer Report 2022" delivered by Alzheimer's Disease International, "Dementia in Europe – Yearbook 2021" issued by Alzheimer Europe, "The National Action Plan for Dementia – Alzheimer's Disease" issued by Alzheimer Athens, Greece, "Global Peer Support Celebration Day (GPSCD)" released by National Association of Peer Supporters, 2018, SUA, "Peer Support for People with Dementia – Resource Pack", HIN 2015, UK.

Some useful documents were offered by Roxana Postolică, clinician psychologist, PhD, psychotherapist, member of Association AFECT and President of Association of Patients with Cancer from lasi, Romania. Romanian partners have supplemented some information upon dementia, respectively issues such as the sudden changes of mood, the repetitive behavior, the stressful behavior, suspicions and doubts of people with dementia and assistance and treatments.

All the materials were translated into Romanian and presented to the participants in a progressive manner. We have managed the time in order to offer an easy to be observed pool of information, to record the goal progress and to monitor the interventions.

Module 1: Introduction to dementia

Learning Outcomes:





Detecting some basic notions about dementia and its impact upon the people diagnosed with dementia, their carers and families.

Ascertaining to the precocious diagnosis of dementia, identification of the care team and the Peer Support Worker - PSW, perceiving the holistic care.

Recognizing the value of experience as the foundation of the future PSW.

Module 2: About the Dementia Friendly Program

Learning Outcomes:

Finding out about the Peer Support Worker – PSW, a novel approach in the Romanian care system.

- Clarifying the operational contexts for a potential PSW in Romania.
- Introducing the Dementia Friendly Program and its 5 key messages.

Module 3: The role of PSW in dementia care

Learning Outcomes:

- Presenting the essential aptitudes and skills of a potential PSW.
- Acknowledging the benefits offered by a PSW to the people with dementia, the caregivers and their families.

Granting the role of the PSW for a healthy lifelong existence and wellbeing of people with dementia.

Module 4: Potential PSW in Romania – supporting our community

Learning Outcomes:

Finding out more about the Peer Support Worker – PSW, who can use his/hers experience and become a support to other carers.

Becoming a Peer Support Worker in Romania and supporting our community.

Module 5: Personal Reflection, Individual Experiences, Stories to be told

Learning Outcomes:

Using the individual experiences as awareness instruments in different meetings.

Identifying the proper communication tools to be used with carers, and decision makers in the area of dementia.

#### Asociatia Habilitas – CRFP (Bucharest):

On November 26 and December 10, as part of the Erasmus+ PIA project, Asociatia Habilitas CRFP conducted the training program for Support Workers in the field of





Dementia within the organization Niciodata singur - prietenii varstnicilor (Never Alone -Friends of the Elderly), together with the association's volunteers and staff, in Bucharest. The program was run for 12 hours.

12 persons aged between 25 and 68, both female and male, from different professional backgrounds, as well as pensioners or students, participated in the piloting of the project.

All 4 modules included in the training program were presented to participants, together with the learning activities included in the program, and adapted to the Romanian context. The material in Romanian language is available for free download at this link.

## Training courses piloting

#### 1. Implementation

After translating and adapting the developed training material, all 5 project partners conducted the pilot between October and December 2022 to test the training with the target groups. The participants recruited had different profiles according to national needs, detailed in the country-by-country pilot reports and in the appendix to this document. Following the common framework of the partnership, the criteria for recruiting participants were to involve key actors who could promote the involvement of Peer Support Workers in the context of caring for people with dementia or profiles who, given their experience as caregivers, could become PSWs themselves. This had a wide impact, on the one hand to raise awareness and promote the role of the Peer Support Worker and on the other hand to enhance the experience of informal caregivers and the role they spontaneously played. Additionally, the duration and subdivision of the training course was decided by each partner, again according to the common framework but taking into account the specific training needs and availability of the participants. This made it possible to ensure a training offer adapted to the specific contexts.

In Norway the course was realised in one day and lasted 8 hours. It was delivered by a trainer (nursing specialist) and involved 8 participants including PSWs, home care nursing staff, managers and volunteers.

In Greece the course lasted 8 hours divided into two days of 4 hours each. It was delivered by a trainer (a psychologist experienced in Alzheimer's care) and involved 9 former caregiver participants.

In Italy, the course lasted 16 hours, of which 12 were face-to-face and 4 autonomous. It was realised in 4 days of 3 hours each by 2 trainers (1 social worker and 1 psychologist) and involved 2 key experts for targeted interventions (1 local social worker and 1 expert in narrative medicine). 6 current and former informal caregivers were involved.





In Romania the course was implemented in 2 cities, lasi and Bucharest. In lasi, the course lasted 16 hours, 12 of which were face-to-face and 4 of which were independent work. It was realised in 4 days of 3 hours each by 2 trainers and 9 participants were involved (5 informal caregivers and 4 volunteers). In Bucharest the course lasted 12 hours divided in 2 days and involved 12 participants with different professional backgrounds, as well as students and pensioners.

#### 2. Participants' evaluation

The course was evaluated very positively by the participants who considered it useful to learn more about the topic of dementia and problems in care. Through the evaluation guestionnaires administered at the end of the training, various aspects concerning the satisfaction and validity of the course were investigated. Overall and with reference to all pilots of the PIA project the following feedback items were given:

- The training was considered by the majority of participants to be useful for performing the role of PSW with a total score of 6.3/7
- The training was clarifying to understand the aspects and tasks of the PSW receiving a final score of 6.3/7
- The duration time and the environment in which the training took place were • considered particularly appropriate, receiving a final score of 6.8/7
- The training was very helpful in developing the skills and abilities to perform the role of PSW in dementia care settings, with an overall rating of 6.5/7
- The dementia knowledge provided in the course was considered sufficient and adequate with a score of 6.4/7

Free comments were also provided via the questionnaire, which allowed for a more concrete analysis of the PIA training course and the collection of final recommendations.

The pilot participants in the various partner countries particularly appreciated the content and the project as a whole. They considered it very balanced in theory and practice, although some would have preferred it to be more dynamic and concrete. In this respect, the interactive activities and exercises, as well as the real-life examples and cases, were particularly appreciated. They considered it very useful to be able to have concrete references in order to assimilate the knowledge provided and would have liked more examples for this purpose. However, some reported feeling somewhat discouraged by the fact that they feel little trust in governments and authorities that they feel are distant and do not simplify things. Among the things that were most appreciated was the fact that so much useful information, both professionally and personally, was conveyed in a simple and clear manner. It was emphasised, however, that it would be important to consider that some people often lack time and that it might be necessary to offer short meetings. The experience was very positively received for its innovativeness and for the open,





welcoming and friendly environment that was created, which left ample space and freedom to express oneself without fear of stigma in order to share knowledge and experiences.

These results confirmed the hypothesis at the basis of the project and the training course, indeed that communication and sharing among peers can be a great help in supporting people experiencing a similar condition. The course can therefore be considered a success, although it is important to adapt it to specific contexts and target groups. It is also important to provide the right support to prevent unpleasant feelings on the part of the participants. The results of this evaluation will be the basis for the finalisation and will be an integral part of the next project results.

### **Facilitators' evaluation**

After piloting, all partners involved in training provision analyses national pilot experiences and results through the SWOT analysis. As internal factors, the Strengths and Weaknesses of partners SWOT analysis have underlined the advantage of the PIA project in a society where there is a huge need for dementia care workers within the healthcare system. However, the figure of the Peer Support Worker is still unknown, unfamiliar and quite difficult to be categorized, as the analysis proved it.

The **Strengths**, as they were described by the partners, underlined the innovation characteristics of the Training Sessions which brought a definitive advantage over the other projects. Is possible to talk about competitiveness in the Nordic countries, but in Italy, Greece and Romania there is a white canvas on which PIA project is drawing the first significant lines. The advantages are clearly of a qualitative nature, somehow difficult to measure but very important (PSW as novelty approach, PSW in dementia which is a well-known healthcare issue, PSW aiming towards raising awareness upon dementia).

- Association KBT affirmed: "there were shared stories and experiences related to the symptoms of dementia with a lot of enthusiasm".
- ANS Italy underlined: "the participants felt very comfortable during the training sessions".
- Alzheimer Hellas stated: "it is very important that there were involved the caregivers as well as the authorities in this new potential role of PSW: it is so important to be a part of the game".
- Asociatia Habilitas specified: "the participants were people with family members with dementia therefore the classes were very thought-provoking".
- From Asociatia AFECT we understood that: "they [the participants] felt like within a family during the training sessions and they have expressed their desire to repeat such sessions and further deepen the knowledge in the field".





The Weaknesses from analysis are referring to some aspects that relate to a certain degree of disadvantage relative to other projects. However, the only country that might encounter such a difficulty is Norway, and yet there are no many projects with regards to the figure of the PSW in dementia. Again, for the other four partners, the lack of such a figure is both an advantage and a loss.

- Association KBT considered as a weak point "the need of further communication" on this subject as well as upon the grieving process".
- ANS Italy stated: "there is no such a formal figure within our dementia care system with which one can share the same experiences".
- Alzheimer Hellas said that "there is a dementia care tradition in Greece but there are no classes taught at the university" and "The participants felt and expressed the fact that they were not ready to become PSW".
- Asociatia Habilitas itemized: "there is no policy approved in this matter in Romania".
- The answer from Asociatia AFECT was that there is a "lack of a real/tangible PSW to explain and clarify the real aspects in dementia care".

On the other hand, the **Opportunities** and **Threats** of this analysis represent the external factors that might indicate a potential growth or risk.

The **Opportunities** are emphasizing those external factors that represent the prospective growth or improvement for the PIA project. This project is clearly addressing several key aspects of our society: healthcare, labor force, education and procedures in all of these. It might be maybe prematurely to speak about PSW as a potential labor force in the market, but we can definitely discuss about changes of social norms that might create new sub-segments of existing markets.

• Association KBT, our most experienced partner in the matter, highlighted several important opportunities: "the project role is to spread the knowledge". "The Training Session might represent the substance of a future officially recognized Training Course in Dementia". "The courses represent a valuable input for the National Plan and for the healthcare workers: Dementia Care + Peer Support Workers". "So far there is no connection between dementia and PSW and this is something we all should aim to". "It is paramount to address the aspect of research in PSW and the implementation of this figure within the fight against dementia". "It would be important to allocate 20% of the academic curricula to the insertion of the PSW in all fields".





- ANS Italy specified: "it is vital to be involved in this system and to influence the decision makers as well as the important stakeholders in this subject".
- Alzheimer Hellas saw as opportunity: "We had the chance to put into practice some techniques of the Theater of the Oppressed".
- Asociatia Habilitas indicated: "the image of the PSW as a trained person to help people with dementia".
- Asociatia AFECT stated that: "the participants have considered the sessions as prospects for a forthcoming career".

The Threats represent somehow the peril of our project in its ability to function and operate. Opposite to the opportunities, the threats can reveal the aspects that can disrupt the flow of the project or even its operation. Considering that there are no real threats within PIA project, we have gathered some answers from our partners that can be labelled more as reservations, taking into account the novelty of the ideas and the lack of the figure of PSW in most of the partner countries.

- KBT Norway, the leading partner: "Without a continuous improvement the interest of the participants' interest might disappear".
- ANS Italy: "We have trained people that for the moment risk to not be involved in such an activity".
- Alzheimer Hellas: "The participants considered the training program to be quite tiresome".
- Asociatia Habilitas: "We do not know when this will be used as we do not have vet a National Plan on Dementia in Romania".
- Asociatia AFECT: "The aspects of some delicate issues discussed within the sessions triggered various emotions (remembering some dear family members gone due to dementia, seeing some of the outcomes of their loved ones within these classes etc.).

Overall, we would like to emphasize the enthusiasms and joy of all the participants to the Training Sessions depicted by our partners, which represent a valuable gain. The uncertainties and reservations of the trainees can also be seen as important points to be further analyzed. Another idea resulting from the analysis is the significance of training, a need that was underlined by most of the trainers and expresses by almost all the participants. Although the volume of the presentations was quite large, the innovative aspect prevailed upon the length. The trainees also noticed that the participants have accomplished their task with pleasure, were creative in their homework and worked harmoniously within their groups.





## Conclusions

Taking care of a person with dementia can be challenging and there is a need to help caregivers develop the necessary skills and knowledge to provide effective care and support. Not just to the person with dementia, but also their family members. The PIA training course is designed to provide caregivers with a deeper understanding of dementia, improve their caregiving techniques, and offer strategies for managing common behavioural challenges.

In the development stage of the work task the partnership needed to consider the specific needs of each partner country:

- Target group (next of kin, informal caregivers, peer support workers, volunteers, or other professional healthcare workers)
- Existing healthcare services (varies from country to country)
- Socio-economic background (varies from country to country)

The training course for caregivers to persons with dementia had several positive effects. An evaluation of the piloting in each partner country showed these benefits:

- Improved Knowledge: The training course provided essential information about dementia, its progression, symptoms, and some caregiving techniques. By increasing their knowledge, caregivers better understood the challenges faced by individuals with dementia and developed appropriate strategies to provide care and support.
- Enhanced Skills: Training equipped caregivers with practical skills necessary for dementia care. They learn effective techniques for providing personal care and assistance. These skills enable caregivers to respond to the changing needs of individuals with dementia and provide quality care.
- Reduced Stress and Burnout: Caring for someone with dementia can be emotionally and physically demanding. Caregivers learned to recognize their own needs, cope with stress, and prevent burnout. This can lead to improved well-being and resilience in their caregiving role.
- Enhanced Safety: Caregivers learned how to create a safe living environment, prevent accidents, and adapt the home to meet the specific needs of individuals with dementia. This knowledge can help reduce the risk of falls, injuries, and other accidents.
- Increased Empathy and Understanding: Caregivers learned the importance of empathy and person-centered care. Caregivers learned to understand and empathize with the experiences of individuals with dementia, fostering a more compassionate and person-centered approach to caregiving.





Improved Quality of Life for Individuals with Dementia: By receiving training, caregivers were better equipped to meet the unique needs of individuals with dementia. They can provide appropriate care, engage individuals in meaningful activities and create a supportive and stimulating environment. These factors contribute to an improved quality of life for individuals with dementia.

It is important to note that the effectiveness of the training course can vary, and the impact may depend on factors such as the national context, quality of the trainers, ongoing support, and the individual needs and circumstances of the caregiver and the person with dementia. Regular assessment and continuous improvement of the training course is essential to enable caregivers to adapt to the changing needs of individuals with dementia.

1. Areas of improvement/unaddressed needs

The evaluation also gave us feedback on topics that the participants meant was important to include in future training courses. These topics are:

- 1. Communication: Dementia can affect a person's ability to communicate effectively. Caregivers saw a need to learn techniques for effective communication with individuals with dementia, such as using simple language, non-verbal cues, and active listening. Improved communication skills can help reduce frustration and enhance the quality of interactions between caregivers and individuals with dementia.
- 2. Ambiguous grief: Also known as unresolved or complicated grief, is a term used to describe the experience of grief that occurs when a loss is not clear-cut or is not openly acknowledged or validated by society. It refers to situations where the loss or the grieving process is ambiguous, uncertain, or unrecognized. These are the two main circumstances that can give rise to ambiguous grief in relatives to persons with dementia:
- 3. Anticipatory Grief: This type of grief occurs when a person anticipates a loss, such as when a loved one is diagnosed with dementia which is a terminal illness. The grieving process begins before the actual death, and the experience can be complicated by feelings of guilt, anxiety, and uncertainty about the future.
- 4. Ambiguous Loss: This occurs when a person is physically present but psychologically absent, such as in the case of dementia. The individual may still be alive, but their personality, memories, or abilities may be significantly altered or diminished.





#### 2. Closing remarks

The partnership acknowledges these unmet needs and concludes to submit a new application with the aim of developing training courses/programs which addresses these needs.





## **ANNEX 1 - Training course piloting in Norway**

The training session was conducted in one day (8 hours) by Mr. Roger Santokhie, Nursing specialist, RN, RMN, Bsc Health management and Public health, KBT Vocational College. The participants were peer support workers, homecare nursing staff, managers and volunteers.

The group composition for the training session was based on the assumption that the training was not just important for peer support workers, but also to educate the other participants of the role of the peer support worker in dementia care.

#### 1. Training evaluation

ltem	Question	Participant 1	Paricipant 2	Paricipant 3	Paricipant 4	Paricipant 5	Participant 6	Paricipant 7	Paricipant 8	Summary
Satisfaction	Usefulness: The training was useful	7	7	7	7	7	6	6	5	6,5
	for me/my roll.									
	Clearness: The traing course has	7	7	7	7	7	6	4	5	6,25
	been clarifying about my roll.									

#### Comments

- Very positive that we can share our experiences with each other.
- Review of the different types of dementia, easy to remember with the use of examples.
- The opportunity to meet and exchange experiences.
- The chance to share experience.
- Good training program.
- Good program
- · Comprehensive and clean PowerPoint presentation.
- Enough information for one sitting.
- Understandable and straightforward language
- · Good training course.
- Help maintain earlier knowledge on dementia.
- Behavioral patterns of the different types of dementia.
- The opportunity to share knowledge and experience and learn from each other.





Item	Question	Participant 1	Paricipant 2	Paricipant 3	Paricipant 4	Paricipant 5	Participant 6	Paricipant 7	Paricipant 8	Summary
Improvements	Was the allocated time and location	7	7	6	7	7	7	6	7	6,75
	conducive for learning?:									
	I developed the necessary skills to	6	7	6	7	7	7	4	6	6,25
	work with persons with dementia									
	and their family.									
	I acquired necessary and sufficient	6	7	6	7	7	7	5	6	6,25
	knowledge of dementia during the									
	course.									
	I feel motivated to work with person	7	7	7	7	7	7	7	7	7
	with dementia and their family									

#### Contents (are there other topics that should be included?)

- Communication with caregivers and the different health services in the county.
- Communication!
- Communication and grieving process.
- More information on communication with persons with dementia and the relatives grieving process.
- Communication with persons with dementia. Especially in the different stages of the illness
- Communication with persons with dementia and the grieving process.

#### General comments.

- Very important to meet each other to exchange experiences
- Exciting project.
- Would like to continue and preferably in a larger position.
- Very helpful with the use of examples, gives a better understanding of training material.
- Very helpful for me.
- Inspiring to share experiences and learn from each other.
- Useful with professional input to supplement acquired knowledge and experience as a relative/caregiver.
- Useful with formal knowledge to supplement acquired lived experience.
- Important to meet and share knowledge and experience.

#### 2. Conclusion

The training course was conducted in a meeting room at a local center, Hovde Gard. The sitting arrangement was in a U-shape, thereby facilitating dialog and eye contact between the participants in the classroom. Participants filled out the standard evaluation form at the end of the training. They were satisfied with the location and classroom environment. They were quite clear with suggestions for improvement.





Some of the participants were adamant about the importance of including communication and ambiguous grief in the training program. This feedback came from the peer support workers that actually had training in communication and interaction with persons with dementia, they meant that communication was their most important work tool. This feedback was the catalyst for work on a new application from the partnership.





## **ANNEX 2 - Training course piloting in Greece**

The training sessions' implementation lasted 8 hours divided in a 4 hours session per one day delivered by Dr Marianna Tsatali, psychologist in the Greek Alzheimer Association in Thessaloniki. Team members constituted 9 ex caregivers who were previously attending support programs in the caregivers' unit of Greek Alzheimer Association. The two training sessions were scheduled in two consecutive days (19-20/12/2022).

The reason why all participants were ex caregivers, is to identify whether those people would feel encouraged and motivated to be future PSW. Given their caregiving experience, it would be easy for them to get in touch again with their previous role as a carer, and therefore see it from another perspective.

#### 1. Training evaluation

Participants completed the questionnaire just after the training sessions, the second day. According to the questionnaire's structure, we intended to figure out whether the following domains would be in favour of our training material's content and therefore constitute a motivational info pack for future PSW. According to the graph below, participants mentioned high levels of satisfaction, clarity, and positive comments about the content material as well as being motivated for being a PSW. It is noteworthy that the majority of them told that the duration of the material should be smaller because they lack of time.





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I developed the necessary skills to use my experience to support other caregivers I acquired sufficient knowledge about the role of PSW The spaces in which the meetings were held and the materials used were adequate The topics and activities were presented and managed appropriately The training course clarified for me who a PSW is and what role he/she can play The training course motivated me to taking part in initiative involving a PSW

However, most of them gave interesting insights, for example, almost all of the group expressed their willingness to continue the course when possible, according to the availability of time.

2. Conclusions

Interestingly, participants had really positive feelings towards the initiative of PSW, highlighting that is really helpful, very humanistic and reflects significant needs of carers as well as people living with dementia. All of them told me that till now being a dementia carer brings lots of challenges which could be managed from volunteers due to the luck of funding, especially in the province. All of them said that they want to be PSW, but they don't have enough time to dedicate on this.

When asked about which was their favourite technique, they said that they prefer the theatre of the oppressed activity.

Below you can find participants' specific comments:

- 2 participants indicated that they do not like the term "employees- workers"
- 1 participant mentioned that is a gift for someone to be a PSW, but they don't need money to do it
- 1 participant wondered whether the role of PSW would trigger memories and flashbacks. She also expressed concerns about PSW causing harm (unintentionally) to caregivers
- regarding the role of PSW the following was mentioned: keeping the patient company, calling them, making them feel good, giving a sweet talk, feelings of warm
- 1 participant would feel satisfaction seeing the patient smile
- 1 participant focused on practical help (having a pool of people to call when the caregiver needs practical help)
- participants emphasized the importance of implementing action in smaller townsvillages
- 1 participant focused on the role of school to promote PSW





- the importance of cooperation with the municipalities was also emphasized by another participant
- the most basic need of caregivers is to find someone to provide practical help
- the best reflective exercise was considered to be the one for self-care (however, there is a question, for example, do I have the right to self-care? Where should I ask for it? From myself- in this, acceptance (of oneself/situation) is important.to accept to join groups, to accept what I missed and didn't catch up.- also a good exercise was considered the theater of the oppressed

Final comments:

- Being a PSW needs loving people
- Another perspective, to see things beyond our nose
- I hope it continues
- I don't expect anything from the government; always caregivers need to take initiatives
- he is happy about new initiatives organized by Greek Alzheimer Association
- Caregivers is an army without weapons (lack of practical materials, delay in receiving money from the government etc)





## **ANNEX 3 - Training course piloting in Italy**

The training lasted a total of 16 divided in 12 hours in synchronous sessions in presence and 4 hours of asynchronous activities at home. The training was implemented into 4 days of 3 hour sessions every two weeks plus 1 hour per session for self-reflections and individual activities. It was implemented by Giusy Trogu, social worker and project manager, and Chiara Lodovici, psychologist and trainer. Considering the specificity of some topics, two key professionals were invited to be part of the training: Anna Masucci, social worker with experience in the field of care, and Licia Boccaletti, ANS president and trainer expert in narrative medicine.

Day 1 – 29/10/22

Introduction to Dementia, the Role of the Caregiver and Principles of the PSW

Trainers: Giusy Trogu and Chiara Lodovici

The first day was useful to make a quick introduction of the participants and to make a brief introduction to the macro topic of dementia and to be clear about how dementia can impact on the person with dementia, on the life and relationship with family members and caregivers.

Another central point that was emphasised was the impact of care and the consequences of stress and burnout on the health and well-being of caregivers.

Day 2 – 12/11/22

The role of the PSW and the contexts in which he/she works

Trainers: Giusy Trogu, Chiara Lodovici and Anna Masucci

The second meeting focused on the Italian context and more specifically on the context of dementia care. In this occasion, Anna Masucci, Social Worker, was invited and helped to give an overview also with respect to the laws regulating the field of dementia and the rights of caregivers.

The objectives and benefits of the figure of the PSW were introduced and clarified, also underlining the differences from the other countries that are part of the project and how this figure can also contribute to raising awareness in the community.

Day 3 - 26/11/22

Skills and strategies of the PSW

Trainers: Giusy Trogu, Chiara Lodovici





During the third meeting, we better analyse which characteristics a PSW should develop and/or increase. Through exercises and reflection, it was useful to deepen issues such as communication, empathy, active listening, and other useful and fundamental attitudes in the relationship between caregiver and PSW. Furthermore, even though the Italian context does not yet recognise the figure of the PSW, we reflected together on the contexts and realities in which the PSW can be inserted.

#### Day 4 - 17/12/22

#### Narrative medicine and the importance of storytelling

#### Trainers: Chiara Lodovici and Licia Boccaletti

The final meeting focused on the importance of storytelling. In this regard, Licia Boccaletti, expert in narrative medicine and project manager, was invited to bring out the stories of our caregivers and to analyse together how this experience was transformative and how some elements can be used by them in their role as PSW. Knowing how to process their own experience as support for other caregivers.

#### 1. Participants to the piloting

The course was conducted with six participants: 2 former caregivers, 3 caregivers and 1 volunteer from an Alzheimer's association who had a caring experience in the past.

The common characteristic of the participants is their experience as caregivers. In fact, the course in Italy was specifically aimed at people who had this kind of experience in their lives. They reflected on the importance of being able to understand situations, of being able to be helpful not only for the notions learned but also for the personal baggage that these caregiver experiences inevitably brought in the life of these individuals.

#### 2. Evaluation of the piloting

The course was evaluated by the participants by a questionnaire. Within the questionnaire, we tried to investigate their satisfaction with the time spent, their prior knowledge and the benefits of the course. Overall, as the graphs below show, satisfaction was high from all participants. All expressed that the course was also useful for them to reflect on their own experience as carers and as potential experts by experience.







However, most of them gave interesting insights, for example, almost all of the group expressed their willingness to continue the course where possible, due to the time factor. In fact, almost all of them emphasized that there were few meetings.

In the space left for comments some of them expressed some concerns about the course being too short, they would have liked it to have lasted longer.

On the other hand, the things they appreciated most were the sharing, the confrontation. One of them said "The confrontation with other Caregivers, it's important, then it led me to new reflections on my experience as a Caregiver".

#### 3. Conclusions

The programme tested in Italy was designed on the specific needs of the context, and during the training it was noted that the participants felt that they were the holders of the needs identified and underlying the structure of the course.

During all the sessions, training that was balanced between theory and practice was offered, leaving the adequate space for sharing experiences, which held a central place in the training. This aspect was particularly appreciated by the participants who





encouraged each other to open up and share their stories. These results confirmed the hypothesis at the base of the project and the training course, indeed that communication and sharing among peers can be a great help in supporting people experiencing a similar condition.

At the beginning of the training course, participants were provided with a notebook to be used throughout the meetings for notes, thoughts and experiences. This was very significant as the caregivers had a diary that accompanied them throughout the learning experience and made it possible to collect some first-hand testimonies of the Italian pilot and their story.

Some participants have already carried out or participated in awareness-raising actions as caregivers of persons with dementia. Most of them actively participate in mutual aid groups, one offered support and information through an Alzheimer's association desk and one wrote and shared his story in a booklet of carers' stories. In this sense, the course was a further reinforcement of the active role that most of the participants play in peer support and awareness-raising. The participants, in fact, recognised the value of the Peer Support Worker figure in the field of dementia and were very interested in having such a figure recognised and applied in the Italian context.

In conclusion, it can be said that the course was a success and received a positive evaluation from both the organisers and the participants. For the repetition it is recommended to use the theory only as a stimulus and framework to stimulate the participants' awareness of their own role. Particularly important is to offer references and links to the territory and existing services, as well as communication and storytelling skills for supporting other peers and sharing one's own stories. However, central and indispensable value must be placed on the experience of potential Peer Support Workers, providing space and facilitating discussion and sharing by participants. In this regard, it is emphasised that the trainers who will implement the PIA course should be able to deliver the training and at the same time act as facilitators, so that the self-awareness and empowerment of carers of persons with dementia is promoted.





## ANNEX 4 - Training course piloting in Romania (lasi)

The training program comprised a number of 4 Modules distributed for a period of 5 weeks, respectively on November 11, 2022, November 19, 2022, November 26, 2022 and December 10, 2022. Each module consisted of 3 hours plus one 1 hour dedicated to personal reflection. The total number of hours of all Training Sessions was 16. The location of the training sessions was in a known area of the city, respectively Podul Ros, attainable with all the means of transportation.

The sessions included video and audio training aids, written documents, tutoring aids such as flip-chart, copy-books, colored pencils, chatterbox cards, different objects for the applied sitting.

A number of 9 participants have joined the Training Sessions, among them 5 were carers – within their families they had people diagnosed with dementia and 4 were volunteers.



Table 1. Participants to the Training Sessions







Table 2. Gender Distribution of the Participants to the Training Sessions

In Table 3 we have added some additional information regarding the Participants to the Training Sessions.

No.	Profession	Age	Gender	Studies
1	Sales operator	26	F	Higher Education
2	Customer Service Operator	28	F	Higher Education
3	Master Student	26	М	Higher Education
4	Master Student	24	М	Higher Education
5	Social Worker	35	F	Higher Education
6	Human Resource Operative	24	F	Higher Education
7	Translator	25	М	Higher Education
8	Social Worker	33	F	Higher Education
9	Social Worker	37	F	Higher Education



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Table 3. Additional Information of the Participants to the Training Sessions

#### 1. Piloting implementation

1<sup>st</sup> Day of the Training: November 11, 2022

Introduction to dementia, early signs, risk factors, care team, dementia awareness

The first day facilitated the meeting of all participants. A presentation of Module 1 was offered under the form of a Power Point.

Some of the written documents were handed out to the interested participants. A list of useful as well as non-recommended expressions for the people with dementia was distributed the participants.

At the end of the presentation a short discussion took place between the participants. The partakers with family members diagnosed with dementia felt stimulated to share some of their views upon the presented material.

Trainers: Atena Gaspar & Petronela Nistor

2<sup>nd</sup> Day of the Training: November 19, 2022

Dementia Friendly Program, 5 key messages, proposed activities within the program

The second meeting within the Training Program presented some aspects of the Dementia Friendly Program. As three of our participants were social-workers it was very helpful to grasp the potential social meaning of the PSW and the programs associated with the wellbeing of the people with dementia.

All participants were encouraged to write down on their notebooks ideas and questions to be clarified by the end of the meeting.

The participants shared their own reflections after the first module. A series of quick Q&A followed.

Trainers: Atena Gaspar & Petronela Nistor

3<sup>rd</sup> Day of the Training: November 26, 2022

The role of PSW in dementia care, the members of the care team, becoming a PSW in Romania

The third meeting was dedicated to the clarification of the roles and characteristics of a future PSW. The presentation aimed to analyze the concepts and possibilities of recovery in relation to mental health care. It was performed an evaluation of the national and international practices and policies relating to PSW. The trainers have also assessed the social and economic contexts correlated to the needs of people with mental health problem and the role of PSW from this perspective. Guiding words: inspiration, hope, empathy, encouragement, recovery.

Some practical activities took place providing the participants with social, cognitive and communication skills in the area of mental health.





Practical exercise: Suggested and not recommended expressions during the communication process with the people with dementia.

The participants shared their own reflections and individual experiences after the second module. A series of quick Q&A followed.

Trainers: Atena Gaspar & Petronela Nistor

4<sup>th</sup> Day of the Training: December 10, 2022

Title: Potential PSW in Romania – supporting our community, reflections of the potential PSW

During the fourth and final module we have addressed the notion of personal growth of a future PSW and the community engagement.

We have addressed the potential PSW skills development in practice with reflection upon own values and understanding of such a potential role.

It emerged the need to foremost adopt and implement the profile of the PSW in the Romanian care system and then to explore PSW as a progressive way to operate with people with dementia.

The participants shared their own reflection after the third module. A series of quick Q&A followed.

Practical activity: all the participants have helped crafted a fir tree dedicated to the project with the flags of all the participant countries and some personal notes written by hand. During the last meeting the participants shared Christmas cards and sweets with each other.

Final comments and remarks followed.

At the end of Module 4 all the participants received Participation Diplomas.

Trainers: Atena Gaspar & Petronela Nistor

#### 2. Evaluation of the Training Courses

At the end of the piloting all participants were asked to complete a questionnaire to evaluate the training program as well as the input of the trainers.

The role of the questionnaire was to determine the degree of satisfaction of the participants, the usefulness of the information, the ratio time vs the distributed content, the importance of the topics and the overall benefits.

#### 2.1 Part 1. Satisfaction

The first multiple choice question (MCQ) aimed the usefulness.

Usefulness: all the participants considered that it was a very beneficial course and that more courses for potential PSW should be available, especially for those with family members diagnosed with dementia.





The second multiple choice question (MCQ) targeted the clarity.

Clarity: Unanimously all the participants have agreed with the comprehensibility of the demonstrations and made them see, in the future, a potential new occupation - PSW in the field of social/medical care.

The first open question "What did you like most?" received the following answers:

- The explanations regarding the potential Peer Support Worker PSW and his/hers skills in working with people diagnosed (or not yet diagnosed) with dementia.
- I enjoyed very much the general atmosphere of this Training Course it was a friendly gathering.
- o I liked the collaboration of all the participants as well as the general style of the communication.
- The information was useful, interesting and novel.
- The togetherness of this group was guite significant. I was able to speak freely about my dear family member diagnosed with dementia.
- A relaxing and friendly ambiance, open discussions and the presence of specialists from different areas of interest.
- The training documents, the video documents and the Power Point presentation, the overall professional manner.
- The comforting atmosphere of all the sessions.
- The examples of a potential Peer Support Worker PSW and the personal reflections of the participants.

All the participants have mentioned that the meetings were very friendly and informal. Everybody had a chance to express their own opinions and views in a very relaxing and comforting environment.

The second open question "What did you like least" received the following answers:

- There are no dislikes to be mentioned regarding this Training Course.
- Not applicable.
- Not applicable.

The third open question "What did you like with this Training Course" received the following answers:

- The new/innovative information about the opportunities for the people with dementia and their carers.
- Clear explanations which have stimulated the open dialogues + well prepared, empathic and open trainers.





- The explanations given regarding the role of a Peer Support Worker PSW and the examples.
- Everything was at its best.
- The explanations were accompanied by examples so that we were able to understand.
- I have acquired new information.
- Very good organization, friendly talks, comprehensive and illustrative information.
- o I have succeeded to enrich my knowledge and to acquire new information.
- The quality and accuracy of the information.

The fourth open question "What did you dislike with this Training Course" received the following answers:

- Not applicable.
- There are no unpleasant aspects to be mentioned.
- I didn't like it was over ...

#### 2.2 Part 2. Improvements

The first open question that was dealing with the content "Do you think that there are other topics that should have been included in this Training Course" received the following answers:

- Some tangible examples about working with people with dementia.
- I think that all relevant information were included.
- o There were presented a series of complex information. The discussion covered almost all about the dementia.
- More practical examples.

The first multiple choice question (MCQ) aimed at the allocated time for the Training Course.

All the participants have selected the box: "totally agreed".

The second multiple choice question (MCQ) intended to identify the skills of a potential PSW. "I have developed the necessary skills to work with people with dementia".

All the participants have selected the box: "totally agreed".

The third multiple choice question (MCQ) envisioned the acquired knowledge. "I have acquired necessary and sufficient knowledge of dementia during the course". All the participants have selected the box: "totally agreed".





The fourth multiple choice question (MCQ) was directed towards the potential motivation of the participants in working with people with dementia. "I feel motivated to work with people with dementia and their families".

Three of the participants have selected the box: "totally agreed". Six of the participants have selected the box: "agreed".

The last item of the questionnaire was dedicated to the comments.

- This Training Course had offered me the chance to reflect upon the 0 possibility of becoming a Peer Support Worker – PSW, provided that this type of job would be available in Romania. The organization was very good and I met special people within this course.
- o Good luck with this project and with the transfer into practice of all the theoretical elements.
- I would like to participate to other training courses on this topic. For those who have in their families people with dementia the opportunity to call for a Peer Support Worker – PSW is extraordinary. Warm congratulations and good luck in the future.
- o I consider that this Training Program was extremely useful, it helped enhanced my general knowledge and it will be useful in the future.
- I wish to be able to partake to more related courses. It is an approach with a huge potential for the activity within the medical or social work area.
- Congratulations for the promotion of such a topic in Romania.

#### 3. Conclusions

The Training Program that was offered in lasi, Romania was very well received by all the participants. Having three social-workers within our group was beneficial for the cohesion and the interconnection that emerged. Five of the participants were carers for family members diagnosed with dementia and Alzheimer's and the course proved to be a worthy break in their busy family schedule and a change to open to the other carers. Even some of the volunteers have identified within their families some members with signs of precocious dementia, which was perceived as a revealing moment.

The open discussions of all participants were fuelled by the presentations and the experiences shared without the apprehension of being judged. One of our volunteers was a disabled person and he felt comfortable from the very first meeting to share with us some of his own inabilities and limitations as well as the stigma associated with. This aspect triggered more acknowledgments and some of the participants/carers followed in sharing their true feelings about the persons with dementia from their care. One of them





said "For me it is now very obvious why my mother is behaving the way she is behaving. It is a revelation, a true revelation ..."

The idea of a new role in the medical/social area, respectively of the Peer Support Worker – PSW was perceived as an outstanding help for the family of a person with dementia. As six of our participants were in their twenties, the prospect of such a job was quite appealing. Of course, the debates were directed towards the necessity to participate to several training courses with practical applicability, which is quite a delicate aspect taken into account the need to identify people with dementia that could be included in such a course.

All participants have stated their content and underlined the fact that during this Training Course they felt like they were a family, being able to discuss very personal issues in a warm and serene environment. The organizers were congratulated for the Training Course that took place in lasi, as the information on PSW in dementia care was new, interesting and stimulating.

The Training Course proved to be a worthy accomplishment and another one, or even more courses, would be very beneficial for the potential Peer Support Worker – PSW in Romania.





## **ANNEX 5 - Training course piloting in Romania (Bucharest)**

On November 26 and December 10, as part of the Erasmus+ PIA project, Asociatia Habilitas CRFP conducted the training program for Support Workers in the field of Dementia within the organization Niciodata singur- prietenii varstnicilor (Never Alone -Friends of the Elderly), together with the association's volunteers and staff. The program was run for 12 hours.

12 persons aged between 25 and 68, both female and male, from different professional backgrounds, as well as pensioners or students, participated in the piloting of the project.

The demographic data of the participants will be presented in the following table:

No.	Profession	Age	Gender
1	Retired	68	female
2	Legal Adviser	47	female
3	Recruitment consultant	35	female
4	Secretary	58	female
5	Economist	30	male
6	Student	32	male
7	Human resources specialist adviser	43	female





8	Human resources specialist	37	female
9	Program manager	36	male
10	Program manager	25	female
11	Executive Director	36	male
12	Sustainability manager	33	female

Following the pilot training program, the participants were asked to complete a questionnaire to evaluate the training activities. The questionnaire is divided into two parts: The first part contains items related to the satisfaction of the participants regarding the training course and the second part contains items related to improvements that can be implemented within the training program. The questionnaire includes both closed questions where the participants evaluated the items on a scale from 1 to 7 where 1 represents "Total disagreement" and 7 represents "Total agreement", but also comment sections or open questions.

#### Centralization of answers from the evaluation guestionnaires

#### The first part. Satisfaction

1. Regarding the first item regarding Usefulness (The training course was useful for *me/my role*) 7 participants totally agreed. The answers of the other participants can be seen in the following graph:









2. Regarding item 2 - Clarity *(The training course was clarifying, about my role)*- 4 participants "Totally agree" and 5 participants "Agree" with the item. The rest of the answers are presented in the following graph:



3. Following are the answers received for the open question - "What did you like or dislike about the training course?"

## a) What did you like the most? - All 12 participants answered this question. Their answers are presented below:





- "The professional approach"

- "The fact that we were able to find out more and our questions were answered"

- "Presentations, conversations, real stories, interactions."

- "Free discussions, group exercises, course format/visual presentation"

- "The course was interactive, concrete solutions were requested."

- "The presentation elaborated and the explanations given"

- "Information received, interesting statistics, group discussions that were initiated and coordinated by the facilitator."

- "The free discussions were very useful"

- "It is a very useful course in terms of interaction with the elderly. Interesting information about ways to organize activities with this category of people. Many useful experiences shared."

- "Existence of a discussion framework about dementia (Congratulations for doing this)"

- 'The opportunity to exchange experience with other people in the field or with similar roles, in order to gain new perspectives'

- "The dementia work model"

#### b) What did you like the least?

- "Certain notions are unclear"

- "In general, short and to the point, without too many exercises to receive information from all participants, is better and more dynamic."

- "The fact that the authorities do not simplify the process."
- "PPT presentation can be improved (content, visual)"
- "The course was a little static"
- "The course support structure should be compacted."





- "Time allocated, few practical models"

#### Part Two - Improvements

4. The second part begins with an open question related to the content of the program -Participants were asked to mention if there are other topics that should be included. The answers of the participants are presented in the following:

-"A job description for the dementia support worker. "

- "One or two videos with real cases or tips for support workers would be welcomed"

- "PPT Support"

- "More examples (visual frames) about what exactly is working with people diagnosed with dementia"

- "The course was complete for the subject covered"
- "I think it would be opportune to exchange experience with other countries."
- "More methods of delivery/ more practical examples."

- "I identified a series of repeated ideas throughout the course. I think it would be appropriate to better structure the course support for a more efficient assimilation of information. "

- "Success stories from support workers from abroad"

5. The second item contained in the second part refers to time and location, more precisely if they were conducive to learning. 5 participants are in "Total agreement" with this item. You can see the rest of the answers provided in the graph below.







This item has a comments section. 9 participants noted in this section. Their answers are presented in the following:

- "I could not always see/read the details on the slides"
- "I think that we talked as much as was necessary about each topic"
- "It was a very good experience at the right time and place"

- "The sessions were sufficient for basic information, but I believe that a program spread over several sessions and with a more applied content would be helpful. The information is not enough to be able to consider that the necessary skills to work with people with dementia have been acquired (I want to know more)"

- "For those who want to work with patients with dementia, they need more information."

- "The time was enough for the discussions related to the course. I appreciate the quality of the material presented."

6. Next item refers to the development of the necessary skills to work with people with dementia and their families (I have developed the skills necessary to work with people with dementia and their families). 2 participants are in "Total Agreement" and 3 "Agree" with this item. You can see the other answers of the participants in the graph below.







7. Regarding the knowledge about dementia acquired during the course (*I acquired necessary and sufficient knowledge about dementia during the course*) 3 participants are in "Total agreement" and another 3 "Agree" with this item. You can see the other answers of the participants in the graph below.



8. The last item before the "general comments" refers to the participants' motivation to work with people with dementia and their families (*I feel motivated to work with people with dementia and their families*). 5 participants are in "Moderate agreement" and





another 5 "Agree" with this item. You can see the other answers of the participants in the graph below.



9. The responses received in the "General Comments" section are presented below:

- "From theory to practice, I think it is a long distance. I am motivated, I am more confident than before, but my skills and knowledge can be better evaluated in practical conditions."

-" It was useful! Thank you!"

- "Very interesting all the information presented and discussed. Thank you! Good luck for the project to finish the theoretical phase and put the assimilated information into practice."

- "The course served as a complement to the information/skills I had, it summarized and put essential points on paper. Practice is the most important to confirm the success of the course. Thank you!"

- "Unfortunately, society and the state do not get involved, but I congratulate the organizers of the course for their involvement and empathy. The facilitators were very involved in the presentation activity, which led to understanding and awareness."

- "I consider it very important that this course be held in several locations."

- "This course helped me to become aware of the fact that in our society there is still not enough support for patients with dementia, nor for their families, and I believe that it is





time to sound the alarm with everything we can. Now I am more attentive to the signals sent by the beneficiary."

- "Very interesting and very useful course for volunteering with the elderly, with a lot of information about appropriate behavior in accompanying them."

- "The subject is very useful and I am sure that even more things can be done in Romania for this cause."

- "I had most of the information from the course, but it helped me to put it in the perspective of the support worker and especially to have an exchange of experience with other people."

- "Thank you!"

