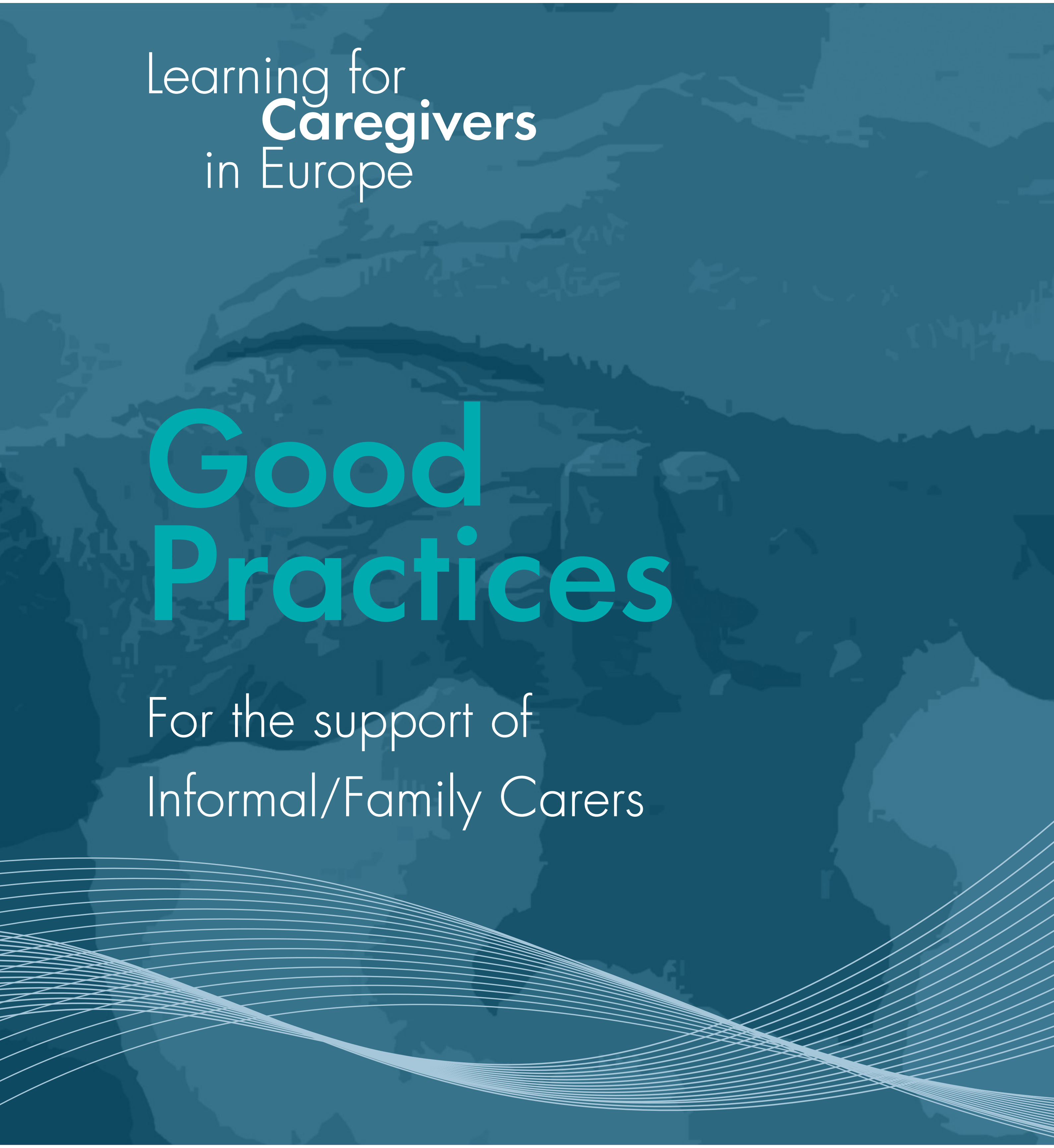
Learn4Carers



Learning for
Caregivers
in Europe

Good Practices

For the support of Informal/Family Carers

Co-funded by the
Erasmus+ Programme
of the European Union

ΙΔΡΥΜΑ ΚΡΑΤΙΚΩΝ ΥΠΟΤΡΟΦΙΩΝ
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Learn4Carers

Introduction

Learn4Carers in a few words

The "Learning for Caregivers in Europe (Learn4Carers)" project targets informal/ family carers and professionals who work with carers directly or indirectly as well as citizens more broadly in Greece, Ireland, France, Belgium and in the rest of Europe. Carers can be defined as persons who provide usually unpaid care to someone with a chronic illness, disability or other long-lasting health or care need, outside a professional or formal framework. Carers carry out, often regularly, significant or substantial caring tasks, and - although caring for a loved one can be a source of great personal satisfaction, it does create its own set of challenges. These can include physical and mental health problems, a feeling of isolation, difficulty in balancing paid work with care responsibilities, perhaps even financial worries as social provisions are cut back.

Within the "Learn4Carers" project we will target carers and professionals working for and with carers of every age group, irrespective of the particular health need of the person they are caring for. As the recognition of carers and the support mechanisms that are available varies significantly across Europe, a transnational approach to establishing support services for carers and sharing good practices for professionals is a promising undertaking. Country-specific strategies will be developed to tackle many of the issues mentioned above.

How will Learn4Carers achieve this?

Each partner will undertake steps in its country to promote the need for more support to carers, initiatives to raise awareness of the issue to citizens, and educative activities to professionals about informal carers needs and support methods, with local partners. Project partners will benefit from each other's experience. Good practices, cases and know-how will be documented in the this document, which will be uploaded in the web. The project aims to exchange of tools and good practices targeting 1) carers, 2) care workers who interact with carers on a regular basis and 3) citizens.

WHY DEVELOPING A CARER-FRIENDLY POLICY ENVIRONMENT IS ESSENTIAL

Meeting the EU population's existing and growing long-term care needs is a major challenge across member states. The policy framework to address this demographic context is experiencing profound changes and, as the modernisation of social protection systems is underway, informal carers are under increasing pressure. More generally, the sustainability and nature of care as we know it is being questioned as a result of the growing gap between the demand for and supply of care services.

This is exacerbated by tighter public budgets in many EU countries. Although most of the policies that affect the daily life of carers are designed and implemented at national and regional level, the main challenges facing care systems growing demand, declining supply, quality and financial sustainability - are consistent across all member states. The negative impact of informal care on carers' daily life is also a common challenge across Europe. While care provision differs greatly between (and sometimes within) Member States, it is clear that all countries need the resource provided by informal carers to prevent a collapse of the entire care system.

Over the last few years, much has been achieved in taking forward the carers' agenda at international, EU and to some extent national and regional level. However, the success of initiatives aiming to address the needs and preference of carers largely depends on the interplay between a broad set of policies in the social, health and employment fields. Yet, policy developments of relevance for carers have often been implemented in a fragmented and uneven manner and have therefore not always resulted in real improvements in carer support, leading - sometimes - to a breakdown in trust between carers and decision-makers and service planners.

Much more needs to be done to achieve practical support on an all-inclusive and multidimensional basis, to connect the dots between existing EU, national and regional policy initiatives and to trigger new ones in support of carers. This overview of Good practices to support informal carers aims to contribute to this by presenting practical measures to address the many dimensions of the carer experience.

EPIONI
GREEK CARERS NETWORK

PEPSAEE
PanHellenic Association for the
Psychosocial Rehabilitation & Work
Re-Integration

Care
Alliance
Ireland

la compagnie
des aidants

EURO
CARERS
European Association Working for Carers

A.

The partnership Learn4Carers

The Learn4Carers Partnership

The **Greek Carers Network EPIONI** is a national non-profit organization established in 2016 by a group of citizens who are caregivers or former caregivers. Its aim is to provide continuous and quality support services for individuals who work as informal, unpaid carers of family members or friends who are struggling with physical or mental illness, disability or addiction. Its services include information and experience sharing on best practices, providing carers with practical advice and emotional support, as well as facilitating the development of problem solving skills.

The **Pan-Hellenic Association for Psycho-social Rehabilitation and Work Integration (PEPSAEE)** is a Scientific Non-Governmental Organization that was established more than 20 years ago (on 1996). It aims at facilitating the social inclusion and work integration of people with severe psychosocial problems. PEPSAEE takes part in the national programme for psychiatric reform in Greece and specializes in supporting, coordinating and empowering rehabilitation and work integration initiatives for people with mental health problems. It and operates three rehabilitation structures: two day centers and one residential house for people with severe mental health illness.

Care Alliance Ireland is the National Network of Voluntary Organizations Supporting Family Carers of Ireland. Its vision is that the role of Family Carers is fully recognised and valued by society in Ireland. It provides support to its member organisations in their direct work with Family Carers through the provision of information, developing research and policy, sharing resources, and instigating opportunities for collaboration. Its membership base includes a wide range of not-for-profit organisations who provide services to Ireland's 391,000 Family Carers.

la compagnie
des aidants

La Compagnie des Aidants, social network, private and secure, offers a free supportive space to share, communicate and help each other, in order to improve the conditions of their life at home. The organization proposes practical and economic solutions, created by caregivers to facilitate the lives of others caregivers and improving the well-being of vulnerable people. La compagnie des aidants is an innovative and efficient solution to decrease stress and find serenity, and also to accompany a relevant weakened by illness, handicap or the old age.

EURO
CARERS
European Association Working for Carers

"Eurocarers" brings together 59 carers' organisations as well as relevant research & development organisations from 27 countries a unique combination that enables evidence-based advocacy. These organisations may function at the EU, national, sub-national or regional level (depending on the structures of national health and social service systems).

Since its creation in 2006, Eurocarers has been working for a future in which caring is recognised and valued, and in which informal carers do not face social exclusion, poverty or discrimination. Since 2009, Eurocarers acts as the secretariat of the European Parliament Interest group on Carers, which brings together more than 30 MEPs from 11 member states.

B.

Good Practices

Listen to my story

Support group using literature

Caregivers of people with dementia are daily experiencing various emotions, which often remain unexpressed due to personal or environmental limitations. As a medium of expression, art can create a safe and fruitful background for externalizing one's feelings. When art is used in groups then its benefits are multiple.

Based on this knowledge, the department of caregivers of Alzheimer Hellas in Thessaloniki has implemented the last two years a very innovative therapeutic intervention with literature and poetry as basic tools. Through the use of creative means (narrative therapy and expressive writing), this therapeutic intervention has been designed to help families of people with dementia express their feelings, find new meaning in their experiences and better adjust to their condition.

Literature and poetry stimulate caregivers to exchange thoughts and experiences. The aim of caregivers' narratives is to give answers to their questions about dementia. Besides oral sharing, the members of the group have been writing their own stories, using expressive and spontaneous writing techniques. Up to now, we have gathered many caregivers' stories, in which the truth of their daily experiences and their feelings are prevalent. As an evolution of this intervention, there has been

Organization	**Alzheimer Hellas**
Contact	makrimarina@yahoo.gr Thessaloniki, Greece
Website	www.alzheimer-hellas.gr
Type of intervention	Support Group
Challenges/ comments/ suggestions (if any)	–
Evidence of efficacy/ impact of intervention (published reports, journal articles, objective data, etc)	Conference presentation in Thessaloniki (March 2016)
Are there any challenges with replicating this intervention in another country or setting?	–
Are there copyright issues with respect to replicating this intervention?	Yes

an attempt to merge all the stories of the caregivers into a single story and then dramatize them with the help of professional actors.

A preliminary step of this work in progress was presented in the conference “caring for caregivers”, which was held in Thessaloniki on 18-20/03/2016. A theatre performance entitled “caregiver's voice” was held in March 2017. At the end of the performance, the spectators shared their emotions and thoughts that were common with caregivers' stories. Caregivers who had written the stories expressed their gratitude for being part of this intervention, as they report that it's very helpful to express deep feelings and to find new meaning in their experiences.

That's why we hope that “listen to my story” will continue its' route and even more personal stories will be written by caregivers, in order for us to understand their world!

“Who am I, grandpa?”

The project entitled “who am I, grandpa?” Is an experiential workshop for children and adolescents, which was designed and carried out by three psychologists, specialized in dementia. The attitude of the children towards patients with dementia is possible to change when they have the opportunity to understand the symptoms, causes and prognosis of dementia and also, to learn new ways of interaction with their grandparents with dementia. The aim of the intervention is to raise awareness and provide information on dementia, facilitate the expression of feelings toward and thoughts about the disease, facilitate the acceptance of diversity, reduce social stigma, and empower participants in their interaction with dementia patients. A plethora of experiential techniques and expressive means were used such as a fairy tale, photography, painting, collage and various group games.

Organization	**Alzheimer Hellas**
Contact	makrimarina@yahoo.gr Thessaloniki, Greece
Website	www.alzheimer-hellas.gr
Type of intervention	Experiential workshop
Challenges/ comments/ suggestions (if any)	The attitude of children towards patients
Evidence of efficacy/ impact of intervention (published reports, journal articles, objective data, etc)	–
Are there any challenges with replicating this intervention in another country or setting?	–
Are there copyright issues with respect to replicating this intervention?	Yes

Caravane “tous aidants”

The Caravane des Aidants aims to reach out to caregivers (who support sick people, to identify them and to provide them with all the information they need for them, for which our social workers welcome them in a friendly and conditional to put them in trust and free speech. Further to the exchange with the social workers, we invite the caregivers to subscribe to the social network of mutual help and exchanges of the caregivers company. Installs for 3 days in ap-hp hospital spaces or parking giants casino in 2018, the caravan was installed on the forecourt of the defense and then inside the hospital pity salpetriere. Nearly 1400 people were met during these two events and, in the wake of this success, we wanted to repeat the operation in the provinces.In 2019, the caravan will move to several cities in France: Paris, Strasbourg, Rouen, La Roche-Sur-Yon, Marseille and Bordeaux.

Organization	**La Compagnie des Aidants**
Contact	Estelle Marchand emarchand@lacompagniedesaidants.org 0176284081 Skype Address: estellemarchand France
Website	https://lacompagniedesaidants.org/
Type of intervention	Access to information and advice about care and caring
Challenges/ comments/ suggestions (if any)	We want to recognize and inform carers about all the available solutions
Evidence of efficacy/ impact of intervention (published reports, journal articles, objective data, etc)	Yes, we have conducted an assessment of the caravan practice. We met about 1000 careers
Are there any challenges with replicating this intervention in another country or setting?	Yes
Are there copyright issues with respect to replicating this intervention?	No

Support of Oncological Patients

PALLIATIVE CARE an urgent need for CAREGIVERS

AGIGMA ZOIS (Touch of Life) was founded to cover the unmet needs for action while observing the daily problems that caregivers of oncology patients are facing. Our support network offers knowledge and guidance to caregivers in order for them to stand effectively and efficiently next to the cancer patients.

We provide personal training & counseling sessions to the caregiver in order that they understand the patient's needs, understanding new situations and assess their strengths. Set boundaries in order to restore balance in the family after diagnosis and protect them from a potential burn-out, a fact that will affect caregivers psychologically, and will diminish their valuable offer & help..

Hrough this step by-step guidance, the caregiver learns that sometimes just being there is more than enough and this is invaluable!

Our team of experts stand by the caregiver and provide guidance, training, support and encouragement in order to help him or her cope

After all, Palliative Care means "I hear you saying... because you are important to me and I will be here for you, all the way, as together we can do better”

Up to now, we have supported over 900 families and we continue...

Organization	**Aggigma zois**
Contact	Christina Nomikou cnomikou@agigmazois.gr Greece
Website	www.agigmazois.gr
Type of intervention	Training and counseling sessions
Challenges/ comments/ suggestions (if any)	–
Evidence of efficacy/ impact of intervention (published reports, journal articles, objective data, etc)	Yes
Are there any challenges with replicating this intervention in another country or setting?	–
Are there copyright issues with respect to replicating this intervention?	Yes

Awareness meeting for health professionals in France

We carried out an awareness meeting with hospital health professionals (nurses, doctors, etc.). During this hour-long meeting, we presented the role of caregivers in the care process, and the main solutions available for caregivers including from our association.

We conduct an awareness meeting with hospital health professionals. We are organizing a meeting which brings together healthcare professionals, hospital management, patient associations and carers. The objective is to allow all the actors to express themselves on this theme and to understand the practices, needs and actions that exist for caregivers. During this meeting, we discuss the role of caregivers in the care of the vulnerable loved one. The floor is given to each person. It is the healthcare professionals who speak first, the patient associations and then the caregivers. The role of the association (the Company of Caregivers) is to allow everyone to express themselves and educate health professionals about caregivers. On average, there are around thirty people present.

Organization	**La Compagnie des Aidants**
Contact	emarchand@lacompagniedesaidants.org
Website	https://lacompagniedesaidants.org/caravane/
Type of intervention	Meeting for health professionals
Challenges/ comments/ suggestions (if any)	–
Evidence of efficacy/ impact of intervention (published reports, journal articles, objective data, etc)	–
Are there any challenges with replicating this intervention in another country or setting?	–
Are there copyright issues with respect to replicating this intervention?	

The short film competition

The 65+ elder rights association, a civil society group, organized in 2015 its first short film competition to raise awareness on the role of older people in Turkey. The submissions it received were mostly focused on aging, sickness, death, and depression. Having hosted two competitions in 2015 and 2016, the association aims to promote images of healthy, and productive older adults. Both amateurs and professionals are welcome to participate with five- to ten-minute films ranging from fiction to documentaries, and winners receive cash prizes.

Organization	**65+ Elder Rights Association**
Contact	Gulustu SALUR bilgi@yaslihaklaridernegi.org +902123431043, Turkey- İstanbul
Website	https://yaslihaklaridernegi.org/en/
Type of intervention	Awareness rising event
Challenges/ comments/ suggestions (if any)	–
Evidence of efficacy/ impact of intervention (published reports, journal articles, objective data, etc)	–
Are there any challenges with replicating this intervention in another country or setting?	–
Are there copyright issues with respect to replicating this intervention?	No

Country Report of Turkey, Ageing and Elderly Services in Turkey

The ageing process has different aspects such as chronological, physiological, biological, psychological, socio-cultural, economic and social, and that each aspect may be a resource that feeds and enriches the ageing process, or pose an obstruction that degrades and worsens it. Here, the most important issue that affects all these dimensions is the scope of services provided to the elderly and the related social policies. This report includes details of ageing and elderly services in Turkey and studies about this subject (November, 2016)

Organization	**Head Of Department Of Care Services For Persons With Disabilities, General Directorate Of Services For Pwd's And The Elderly**
Contact	
Website	https://www.unece.org/fileadmin/dam/pau/age/country_rpts/2017/tur_report.pdf
Type of intervention	Assessment of carer needs
Challenges/ comments/ suggestions (if any)	The report can be based as reference for the ageing and elderly care
Evidence of efficacy/ impact of intervention (published reports, journal articles, objective data, etc)	–
Are there any challenges with replicating this intervention in another country or setting?	–
Are there copyright issues with respect to replicating this intervention?	No

Development of Institutional Capacity in Social Inclusion Policies

Some of the activities planned under the development of policy and implementation capabilities of our ministry and relevant stakeholders working in the field of social policy are as follows:

Field researches in thematic areas.

Projection in the area of poverty and social inclusion.

Establishment of Online Social Policy Library and Information Center Developing Professional Standards for Social Workers.

Some of the activities planned to improve policy.

Monitoring and evaluation capacity in the field of social policy.

Organization	**Ministry of Family Labor and Social Services**
Contact	Coskun GURBOGA, Head of Elderly Care Services Department disiliskiler@ailevecalisma.gov.tr bilgiedinme.eyhgm@ailevecalisma.gov.tr +90 (312) 705 70 00 Turkey - Ankara
Website	https://eyh.aile.gov.tr/haberler/alzheimer-ve-diger-demansli-hastalara-bakim-ve-yaklasimmodelleri-calistayi
Type of intervention	Social inclusion (for example: peer support groups, measures enabling carers to combine work and care, etc.)
Challenges/ comments/ suggestions (if any)	It would be great so spread the word and translate our courses (to other languages)
Evidence of efficacy/ impact of intervention (published reports, journal articles, objective data, etc)	–
Are there any challenges with replicating this intervention in another country or setting?	–
Are there copyright issues with respect to replicating this intervention?	No

Establishing workshops on determining social policy indicators and measurement methods in the field of social inclusion. Organizing training program on evaluation of social policies and impact analysis.

Providing support to meet the needs of the units within the scope of full time consultancy.

A report was prepared within the scope of the project; then, Coώgun Górboπa, Head of Department of Elderly Care Services from the Ministry of Family and Social Policies, project experts, UK King Górs College London Social Sciences and Public Policy Social Care Labor Force Research Unit President. Dr. Sheeren hussein, Ankara University, Faculty of Health Sciences, Department of Social Work dr. Emine Φzmete held a workshop on December 7, 2016.

Training of informal caregivers in elderly care

Online care-courses for unpaid caregivers

Aim of this project was to create a unique, innovative and interactive education module including software applications and written publications which will enhance the abilities of informal caregivers in elderly care, within the bio-psychological approach. With this project, it is intended to develop an educational methodology, having social perspectives, within the European Union (eu) to improve, share and apply qualifed teaching, training, and learning strategies and experiences promoting social benefits and innovations. Adult people who take primary care of a 65-year-old and above individual with chronic disease and have not received any training on the care of elderly people were targeted.

The primary objectives of the project were;

To determine the needs of caregivers in elderly care

To provide learning, training, teaching activities by developing an educational module (written and visual) for informal caregivers

To create a web portal for knowledge transfer between informal care givers and health professionals and among informal caregivers

Organization	**Başkent University Faculty Of Health Sciences-Turkey**
Contact	http://traceproje.eu/ Turkey- Ankara
Website	http://www.traceproje.eu/
Type of intervention	Training and recognition of carers' skills
Challenges/ comments/ suggestions (if any)	–
Evidence of efficacy/ impact of intervention (published reports, journal articles, objective data, etc)	–
Are there any challenges with replicating this intervention in another country or setting?	–
Are there copyright issues with respect to replicating this intervention?	No

To create an elderly care knowledge center for informal caregivers and public dissemination of the education module.

Project included 7 work packages including literature review, needs analysis, development of training program, creating mobile applications, pilot testing, analysis of the impact of the training program and dissemination. Five transnational meetings and four short-term learning, training and teaching visits were conducted.

In order to reach the project objectives the following activities were carried out:

Systematic literature review on methodologies used to identify the effect of different types of training on informal caregivers and their elderly. Findings revealed that support interventions for caregivers can be effective in reducing caregivers' stress, with a consequent improvement in the quality of care.

Qualitative research to explore the experiences and needs of informal caregivers in four countries: Italy, Lithuania, The Netherlands and Turkey. Respondents of the qualitative research were adult people who take primary care of a 65-year-old and above individual with a chronic disease. A relevant sampling was conducted in each country. Data were collected from a total of 72 (Turkey: 24, Lithuania: 12, The Netherlands: 20 and Italy: 16) informal caregivers using focus groups or individual interview techniques. The semistructured interviews were conducted in their mother tongue and inductive content analysis was performed on the data from all the countries.

The training module was developed to improve the informal caregivers' capabilities in elderly care. The educational modules were derived from qualitative interviews with 72 individuals from four countries. Under physical care and psychosocial issues modules seven subjects were identified: 1-providing self-care; 2-fall prevention, exercise, moving and transfer; 3- first aid, 4-nutrition, 5-psycho-social changes, 6-communication with elderly, 7-burnout and coping with stress. The training modules context were transferred to the project website: http://www.traceproje.eu/training

National Carers Week

Beginning in 2007, the project brings together range of voluntary organisations to deliver a vibrant week of celebration and the promotion of family carers leading to a fuller appreciation of the value and contribution of family carers.

Objectives

1. To raise awareness of family carers in our community.
2. To deliver events for family carers throughout the country.
3. To engage with family carers not yet availing of carer support services.

Organisation	**Care Alliance Ireland**
Contact	Liam O 'Sullivan info@carealliance.ie +353 87 207 3265, Ireland
Website	www.carersweek.ie
Type of intervention	Carers' health and wellbeing
Challenges/ comments/ suggestions (if any)	Building engagement and participation in these projects takes time. Having a clear focus on the objectives helps. Think big but begin small. Be careful not to duplicate others work. Use celebrities to gain media attention (for example pre-launch photoshoot) Having dedicated funds to spend on merchandise is helpful. Should the focus of the week be primarily on the burden of care or alternatively on recognising and celebrating carers contributions? We have gone with the latter as there are other media and representative opportunities to push the issue of burden and inadequate support services. Difficult to secure corporate sponsorship due to the short duration of the event (week long as opposed to year long.)

	In our evaluations, significant number of family carers report frustration with the week - many are unable to take part in direct face-to-face events - we have therefore put a greater emphasis on sending better merchandise by post to such carers.
Evidence of efficacy/ impact of intervention (published reports, journal articles, objective data, etc)	Difficult to say. We undertake a comprehensive evaluation annually and share the report with partners and potential funders. Feedback is largely positive. Full report available on request.
Are there any challenges with replicating this intervention in another country or setting?	Building relationships with condition specific NGO's. Securing funds to purchase and distribute merchandise. Low awareness and understanding of the term “family carer”.
Are there copyright issues with respect to replicating this intervention?	No

Using Facebook to support family carers

Using a Facebook Page to Support Family carers - through posts, sharing of information, peer support, facilitation of primary research to advance carers issues. Ongoing duration (set up in 2012). >22,000 followers currently. Family Carers and former family carers are the target audience

Gaining traction with recruiting followers would benefit by having funds to secure followers through paid Facebook posts. Crafting helpful posts is time consuming.

A variety of posts using images helps with reach. Having a budget to recruit followers is important.

Organisation	**Care Alliance Ireland**
Contact	Liam O 'Sullivan info@carealliance.ie +353 87 207 3265, Ireland
Website	www.carersweek.ie
Type of intervention	ICT- based solution targeted at carers
Challenges/ comments/ suggestions (if any)	Event feature not useful - people say online - 'attending' but the vast majority will not. Having a separate project "national carers week" connected with the page helps with a focus for follower recruitment.
Evidence of efficacy/ impact of intervention (published reports, journal articles, objective data, etc)	Paper submitted in Dec 2018 to journal of technology in human services. See pdf uploaded above
Are there any challenges with replicating this intervention in another country or setting?	The name of the page may warrant consideration - something like family carers Ireland might be better - but for the fact that there is already such an organisation in existence in Ireland.
Are there copyright issues with respect to replicating this intervention?	No

Some level of moderation required but surprisingly little sharing of other social media posts can be helpful. Targeting of paid posts can reach specific audiences (eg dementia carers, male carers etc)

Discover Skills for carers Discover4Carers

Discover skills for carers is an on line social network created through a pan-european project. The network offers information, advice, guidance and training to support the wellbeing of carers and to develop their digital skills. There are more than 1,000 users comprising informal and formal carers, volunteers, care organisations and policymakers. (project duration: 2012-2014)

Organization	**Eurocarers**
Contact	Stecy Yghemonos sy@eurocarers.org 0032456141950 Skype Address: eurocarers-exdir Pan-European
Website	http://www.discover4carers.eu
Type of intervention	Access to information and advice about care and caring
Challenges/ comments/ suggestions (if any)	The main motivation was that digital technologies can transform the experience of carers and their care recipients. However, this requires that familiarity with these technologies, which discover intends to facilitate there are many web sites providing useful information on a range of topics (health, housing, finance and support) and DISCOVER's purpose is to select the best websites and to make them accessible. Similarly, handheld devices as mobile phones can potentially improve communication between formal and informal carers. Many informal carers find it helpful to meet through local support groups. However, some informal carers cannot attend such groups due to their heavy care burden. another driver is that sometimes informal carers are unaware of the support and the services that are available.

Evidence of efficacy/ impact of intervention (published reports, journal articles, objective data, etc)	Strengths: contents of the service are based on the effective needs of users. weaknesses: no impact assessment is available. opportunities: discover is accessible even to people with limited or no experience of using online social networks thanks to guides. discover allows informal carers to interact with each other and create social networks. this aspect is an opportunity to reach new users. threats: limited shelf-life (funding) for the project.
Are there any challenges with replicating this intervention in another country or setting?	–
Are there copyright issues with respect to replicating this intervention?	No

Caren

Caren is a personal healthcare portal aiming to help informal and formal carers organise and coordinate assistance and share information, created by the NEDAP business unit healthcare, which is a provider of technological solutions in different sectors (http://www.nedap.com/about-nedap/). The service is free-of-charge and privately financed with investments and revenue from other ICT services.

There are more than 8,000 users, which are increasing. Carers either receive a login code by Caren operators or they sign up for a free account. By means of a Caren account, regional care centres offer different and user friendly services to carers while maintaining their privacy. Caren intends to improve its sustainability by means of outside long term investments as the service is profitable and is able to increase its revenue. The initiative works due to the professionalism of health and social carers as well as of private companies.

Caren could improve the quality of life of informal and formal carers and their patients, foster cost savings for private care organisations. At the macro level Caren

Organization	**Eurocarers**
Contact	Stecy Yghemonos sy@eurocarers.org 0032456141950 Skype Address: eurocarers-exdir Netherlands
Website	https://carensorgt.nl
Type of intervention	–
Challenges/ comments/ suggestions (if any)	–
Evidence of efficacy/ impact of intervention (published reports, journal articles, objective data, etc)	–
Are there any challenges with replicating this intervention in another country or setting?	–
Are there copyright issues with respect to replicating this intervention?	–

could positively affect the public health care system by reducing spending for home caring and hospitalisation. The service is widespread only in the Netherlands. Notwithstanding this, the service addresses many target groups within the care sector and is set up as an international platform in multiple languages.

Curendo Pflegecoach

Online care-courses for unpaid caregivers

We have implemented three online-courses for unpaid caregivers. The courses are available since 2015 and are covered by health insurance. Results of scientific evaluation have been published. Thousands of caregivers have joined.

The interactive online care courses "Fundamentals of Home Care" and "Dementia", available at curendo.de, allow relatives and volunteers to prepare online for care in the home environment.

The online care courses are based on the methodical-didactic principles and contents of real care courses, but also make use of the possibilities of the internet, eg: Self-directed learning, self-tests or animations. All information contained in the online courses is presented in an attractive, easy to understand and motivating format. The learning content is tailored to the learner's needs with easy-to-use and self-explanatory interactions.

The online courses are led by nursing advisers who answer questions within 48 hours. There is no medical or legal advice. The data hosting of the course platform takes place in accordance with the data protection and security guidelines and the Federal Data Protection Act.

Organization	**Töechter & Söhne Gesselschaft für Helfer mbH**
Contact	Caspari Caspari@toechtersoehne.com Germany
Website	https://pflege.curendo.de
Type of intervention	Online course
Challenges/ comments/ suggestions (if any)	It would be great so spread the word and translate our courses (to other languages)
Evidence of efficacy/ impact of intervention (published reports, journal articles, objective data, etc)	–
Are there any challenges with replicating this intervention in another country or setting?	–
Are there copyright issues with respect to replicating this intervention?	Yes

In particular, online courses offer time and location-independent availability. This and the fact that there are hardly any capacity limits in terms of the number of participants can lead to significant cost savings. Online courses are particularly suitable for teaching and refreshing knowledge. In addition, online courses offer the opportunity to thematize shameful and taboo topics in an anonym protected environment.

Evaluation of the courses are, in addition to the scientific substantiation of the content, crucial quality criteria for Töchter & Söhne. An evaluation of the online nursing courses by the University of Applied Sciences Bremen serves the quality assurance and further development of the courses.

Carer Positive

Carer positive is a Scottish Government funded initiative, developed with the support of a strong partnership between private, public and voluntary sector organisations in Scotland.

Carer positive is operated by carers Scotland on behalf of the Scottish government. In 2011, a 'caring for carers' scheme was listed as one of the Scottish Government's ten manifesto commitments for carers. The aim of this commitment was to “recognise those employers who offer the best support to carers, allowing them the flexibility they often need to deliver care at home.”

Organization	**Töechter & Söhne Gesselschaft für Helfer mbH**
Contact	Stecy Yghemonos Sy@eurocarers.org 0032456141950 Skype Address: eurocarers-exdir Scotland, UK
Website	http://www.carerpositive.org
Type of intervention	Social inclusion (for example: peer support groups, measures allowing carers to combine work and care, etc)
Challenges/ comments/ suggestions (if any)	–
Evidence of efficacy/ impact of intervention (published reports, journal articles, objective data, etc)	Although no evaluation of the initiative has been carried out, evidence has shown that supportive policies and working practices: attracts and retains staff, reduces stress and sickness absence, reduces recruitment and training costs, increases resilience and productivity, improves service delivery, produces cost savings, and improves people management and staff morale Are there any challenges with replicating this intervention in another country and or setting?
Are there any challenges with replicating this intervention in another country or setting?	–
Are there copyright issues with respect to replicating this intervention?	No

Carers Scotland was selected to take this commitment forward and developed the initiative as the carer positive awards. An advisory group of key stakeholders was brought together in order to support the development of the initiative, and a wide range of employers across Scotland were consulted to ensure that it would be accessible to organisations of all sizes and across all sectors.

The carer positive advisory group has included: NHS; Scottish chambers of commerce; Scottish Council for Development and Industry; Federation of Small Businesses; Institute of Directors; the Chartered Institute of Personnel and Development; carers organisations; British Telecom; British Gas; HMRC, the Scottish Court Service, STUC; unison; Healthy Working Lives and 'see me' Scotland.

Integrating Patients and Caregivers in the training of Palliative Health Care Professionals

The intervention took place from June 2018 until June of 2019. Two patients and one caregiver were selected with certain specific criteria and were trained by a university medical professor and a senior psychologist. The training lasted 8 weeks in 4 three-hour sessions.

The patients and the caregiver were then integrated in the training of 44 health care professionals. The health care professionals work in a multidisciplinary home care setting (doctors, nurses, psychologists, social workers and physiotherapists). Five full training workshops took place spread over 8 months.

The aim was to fully integrate the patients and caregivers perspective of the care they received by the health system. The goal was a success and had a profound and

Organization	**PASYKAF (Pancyprian Association of Cancer Patients and Friends)**
Contact	Antonis Tryphonos antonis@pasykaf.org 0035799513205 Skype Address: Antonis.tryphonos Cyprus-Nicosia
Website	https://pasykaf.org/en/home-page/
Type of intervention	Integrated care (in other words: coordination between informal carers and social and health care professionals)
Challenges/ comments/ suggestions (if any)	Profound memorable impact on both patients-caregivers and health care professionals.
Evidence of efficacy/ impact of intervention (published reports, journal articles, objective data, etc)	Paper under publication review
Are there any challenges with replicating this intervention in another country or setting?	There are always challenges
Are there copyright issues with respect to replicating this intervention?	Yes

lasting effect on the patients-caregivers and health care professionals alike. For the first time in Cyprus, patients and caregivers sat around the same table as equals and shared insights and experiences of what it means to receive and provide care.

Themes of the workshops included compassionate care (compassion fatigue, empathy, therapeutic relationship), self-care (spiritual care, lifestyle interventions, stress management), communication (MDT, conflict resolution, managing relationships) and change management (leadership in health care).

Annual Event at the office of the European Parliament in Greece

EPIONI on September the 28th 2018, organised at the office of the European Parliament in Athens, a conference focusing on young caregivers. The event was under the auspices of the Ministry of Health in Greece, the World Federation for Mental Health, the Hellenic Psychiatric Association, and the European Brain Council.

The Commission advocates the introduction of a new entitlement for caregivers, which includes a five-days compensated Carers leave per worker per year, which should be compensated no less than a compensated sick leave. Additionally, the Commission advocates the entitlement of flexible working arrangements for the same reason said the European Commissioner for Health and Food Safety Vytenis Andriukaitis. (Video Message)

In the conference, prominent scientists such as Professor of Psychiatry George Christodoulou, Dr Dimitrios Kontis, Dr Kalliopi Panagiotopoulou, Mr. Panagiotis Chondros from NGO EPAPSY, Dr. George Pavlidis from the University of Sheffield

Organization	**EPIONI Greek Carers Network**
Contact	Spyridon Zormpas szorbas@gmail.com +306946003522 Skype Address: Spyros.zorbas Athens, Greece
Website	https://epioni.gr/en/
Type of intervention	Access to information and advice about care and Caring
Challenges/ comments/ suggestions (if any)	An annual event named Caring for Carers. The venue has a capacity of 70 people
Evidence of efficacy/ impact of intervention (published reports, journal articles, objective data, etc)	–
Are there any challenges with replicating this intervention in another country or setting?	It is a usefull intervention that can be replicated in other EU countries
Are there copyright issues with respect to replicating this intervention?	No

and Mr. Alexandros Oikonomou from NGO EDRA gave insights about long term care. Other prominent speakers included Mr. Stecy Yghemonos, Executive Director of Eurocarers, Mrs Miia Männikkö, President of EUFAMI and Professor Peykan Gokalp from Turkey. The event which had the support of the European Parliament office in Greece and the European Commission Representation in Greece gave the opportunity to caregivers such as Mrs Dragana Kistner from Germany and Mrs. Stefania Buoni, president and founder of COMIP from Italy to share their personal experiences and discuss the challenges involved in caregiving.

Mr Lorenzo Mannu shared his experience from the perspective of civil service in Italy.The conference was organized by EPIONI with the support of MEP from Czech Republic, Mr Tomas Zdechovsky (Welcome Speech), former MEP Mr Nikos Chrysogelos and MEP from Greece Mrs Kostadinka Kuneva.

Former minister of Education and Health Mrs Marietta Giannakou delivered a welcome speech.

Brain Awareness Event for Caregivers in Athens

On the 13th of March 2018, at the Biomedical Research Foundation of the Academy of Athens (BRFAA), the Greek Carers Network EPIONI hold a workshop on the topic "Caring for the caregiver: connecting to clinical and basic research update resources". The event was under the auspices of the World Federation for Mental Health, the Greek Psychiatric Society, and the European Brain Council.

The discussants were eminent mental health scientists such as Professor Georgios Christodoulou, former president of the World Federation for Mental Health, Mr Dimitrios Kontis, assistant professor of Psychiatry, Professor Magda Tsolaki, neurologist-psychiatrist and president of the Panhellenic Federation for Alzheimer's and Related Disorders, Dr Kelly Panagiotopoulou allergologist- group therapist. Mrs Magdi Birtha from COFACE Families Europe presented the 2017 "Who Cares?" European survey for Caregivers. Psychologist Panagiotis Chondros from EPAPSY and Susan Gregory made presentations about carers associations in Greece. Mrs Mary Adamopoulou from EUPATI Greece shared her experience as a Fellow of the

Organization	**EPIONI Greek Carers Network**
Contact	Spyridon Zormpas infoepioni@gmail.com +30 6946003522 Skype Address: spyros.zorbas Athens, Greece
Website	https://epioni.gr/en/
Type of intervention	Carers' health and wellbeing
Challenges/ comments/ suggestions (if any)	The venue was very convenient but not so easily accessible
Evidence of efficacy/ impact of intervention (published reports, journal articles, objective data, etc)	–
Are there any challenges with replicating this intervention in another country or setting?	Good intervention to replicate in another EU country during Brain Awareness
Are there copyright issues with respect to replicating this intervention?	No

Academy and Professor Aris Charonis presented the activities of the BBMRI-ERIC network in Greece. Moderator was Orestis Giotakos.

The Brain Awareness event was conducted with the support of researcher Professor Dimitra Magoura who, aside from her interesting presentation offered an interactive tour of the laboratories of the Biomedical Research Foundation of the Academy of Athens (BRFAA). Participants experienced the way research is done in one of the most modern research centres in Europe.

Event for the new EU Directive for caregivers

EPIONI successfully organized its 3rd flagship annual event on 27.9.19 at the office of the European Parliament in Athens focusing on informal carers. The event was held under the auspices of the Ministry of Health, the Municipality of Athens, the Hellenic Psychiatric Association and WFMH.The event referred in detail to the new European directive which is of particular interest to working family caregivers as it provides for the entitlement to a minimum of 5 days of caregiver leave per year and the right to flexible working arrangements, or work from home for a period of up to six months. A spokesman for the Ministry of Health agreed on the need to educate family carers on the above entitlement.The new directive provides that member states will take the necessary measures to protect working carers from discrimination or dismissal as a result of the exercise of these rights. The abovementioned directive promotes dialogue on work-life balance. All participants agreed that the directive does not solve the major problems of working or non-family carers but it is the first step.

The event featured notable speakers such as professor of psychiatry Mr. George Christodoulou, Dr. Dimitrios Kontis, Dr. Kalliopi Panagiotopoulou Ms. Nadia Kamel on behalf of Eurocarers, Ms. Donna Walsh, Director of EFNA, Professor Philip Gorwood, President of the European Psychiatric Association (EPA), and Dr. Claudia

Organization	**EPIONI Greek Carers Network**
Contact	Spyridon Zormpas
Website	https://epioni.gr/en/
Type of intervention	Awareness Event
Challenges/ comments/ suggestions (if any)	To engage local politicians
Evidence of efficacy/ impact of intervention (published reports, journal articles, objective data, etc)	–
Are there any challenges with replicating this intervention in another country or setting?	It is a good practice to involve the office of the European Parliament in EU countries.
Are there copyright issues with respect to replicating this intervention?	No

Marinetti, Director of Mental Health Europe All discussed in detail the European dimension of support for carers.The event also featured MEP Stelios Kymbouropoulos and MP Marietta Giannakou who delivered a welcome speech referring to the need for implementing the new directive in Greece and for informing carers about their established rights. Mr. Harris Kountouros, representing the European Parliament's office in Greece, said that the European Parliament recognizes the important contribution of carers.

Focus group for carers of people with mental health problems

One meeting which lasted 1,5 hours. Its aim was the exchange of information and opinions about the good practices for carers of people with mental health issues. The participants were unpaid carers of people with mental health problems who receive services from the day center, members of staff from the PEPSAEE Day Centre at 8, Alkamenous St., and representatives of organisations specialising in the support of informal/unpaid carers in other countries. A definition of "carer" was discussed, and many people were motivated to talk about their role and their personal experience. Funding and social benefits were discussed as means addressing the urgent needs of carers. The participants were provided with an opportunity to record the challenges experienced by the carers in Greece. Many requests and ideas have arisen through this process and have been documented, as well as the creation of an action plan concerning the next steps towards the relief of the burden the carers bare with them. The participants documented sharing and exchange of opinions were of great importance to them, they felt included and valued.

Organization	**PEPSAEE**
Contact	Kotsini Ivi kentroimeras@pepsaee.gr Tel. +302108257112
Website	http://www.pepsaee.gr/
Type of intervention	Identification of carers
Challenges/ comments/ suggestions (if any)	–
Evidence of efficacy/ impact of intervention (published reports, journal articles, objective data, etc)	–
Are there any challenges with replicating this intervention in another country or setting?	No
Are there copyright issues with respect to replicating this intervention?	No

Event for caregivers of people with mental health problems

The event for carers took place on Monday, December 2, 2019, 17.00-19.30, at Alkamenous 8. The event featured speeches from mental health professionals. Relatives and carers of people receiving daycare services were invited.

The event lasted 3 hours. Professionals provided speeches concerning the care for carers, and carers of people with mental health issues shared their views and experiences. It was an opportunity to share thoughts and point out the needs of this group.Friends, family and carers of people with mental health issues to whom the day care provides services were invited to participate and exchange opinions.

A representative from PEPSAEE presented the services provided and actions performed for carers. In addition to informing them about their actions, EPIONI shared the developments at the European level for carers. A mental health professional from the field gave his perspective on carer care and spoke about carers' definition and role.

Organization	**PEPSAEE**
Contact	Kotsini Ivi kentroimeras@pepsaee.gr Tel. +302108257112
Website	http://www.pepsaee.gr/
Type of intervention	Assessment of carers' needs
Challenges/ comments/ suggestions (if any)	The participants were given a voice. It was very important to them to share their thoughts and experiences, while identifying their needs and share their concerns
Evidence of efficacy/ impact of intervention (published reports, journal articles, objective data, etc)	–
Are there any challenges with replicating this intervention in another country or setting?	No
Are there copyright issues with respect to replicating this intervention?	No

Support group for relatives of people with mental health issues

Period of time: October 2018 June 2019

Duration 1 hour and a half

Target group: parents of people who have mental health issues.

Aim: To discuss and develop certain modules of interest of the participants, which will enable them to have a better understanding of the kind of challenges their relatives with mental health issues are dealing with. Another aim is the provision of information and support concerning problems in the wider family network which are created due to the mental health issues of the members of the family. An important part of the sessions concerned the relatives' perception of how they themselves were experiencing and feeling the situation inside their own family, focusing on the thoughts, sentiments and the problems the are dealing with a parent-carer.

Organization	**PEPSAEE**
Contact	Kotsini Ivi kentroimeras@pepsaee.gr Tel. +302108257112
Website	http://www.pepsaee.gr/
Type of intervention	Carers' health and wellbeing
Challenges/ comments/ suggestions (if any)	There was positive feedback from the participants. The need of carers to be informed about their role was pointed out.
Evidence of efficacy/ impact of intervention (published reports, journal articles, objective data, etc)	Ongoing process
Are there any challenges with replicating this intervention in another country or setting?	No
Are there copyright issues with respect to replicating this intervention?	No

Kick-off meeting at the office of the European Parliament in Greece

Focus group for caregivers of people with mental health problems at the PEPSAEE Day Center in Athens

Focus Group with family carers in Ireland during the Learn4Carers transnational project meeting in Dublin (17.9.2019)

Stimulating discussions about sharing good practices in family carer support kindly supported and hosted by Mental Health Ireland in Dublin. (16.9.2020)

C.

Advice for professionals working with family caregivers

Advice for professionals working with family caregivers

Maintaining the family in treatment*

Once the family attends the first session, the main task is to encourage them to continue with the sessions. Reasons for stopping include:

a) Previous bad experiences with offers of help

b) Conflicting or unrealistic expectations of intervention

c) Pessimism about the outcome

d) Family members feel blamed for the illness

f) the family does not continue with the intervention they will not benefit.

It is important to find out:

a) The family's past experience with professional help

b) What they expect from you

c) Any negative feelings about what can be achieved

You will have to try to give hope and explain what can be realistically expected from your intervention.

Family supports

Many affected families gradually become isolated from their families and

Friends. You can ask the family members what they each do to distract themselves

from the problems of living with the patient.

- Do they have contacts outside of the family whom they spend time withaside of working hours?
- Does the family approach, anyone, outside the immediate family at crisis times?
- What are the difficulties experienced by the family in caring?
- Are the contacts able to provide support?
- What kind of support do they provide?
- Do they offer to supervise the patient while the family goes out?
- Do they offer financial support?
- Do they advise the family as to what they should do?
- Do they listen to the problems of the family and help them emotionally to cope?

Family responses

You will need to ask the family members about how they feel about the problem

- They may deny or have difficulties accepting that the relative has a problem.
- They may get angry about the problem
- They may feel envious of others
- They may think 'why did this happen to me?'
- They make promises to cure the illness, such as 'I promise to pray everyday if he is cured of this illness'
- They feel depressed when they are no longer able to cope. The financial burdens, the older person's inability to work, stigma, etc, increase these feelings
- They continue to hope for a cure, the discovery of new medication that will improve the symptoms this helps them to cope with their problems

Who does what?

In every family, each member contributes in different ways. You will need to ask them questions like

- 'Which members help in the household chores?'
- 'Who are the breadwinners?'
- 'When the family members are upset, which member do they approach to discuss their problems?'
- 'Who is the head of the family?'
- Are they meeting the expectations of other family members?

Some members may be stressed by having too many roles to play. For example, the mother may be the breadwinner, the housekeeper, the mother to the children, and the caregiver of the older person with dementia.

How do family members communicate?

- Do family members show sympathy and understanding or do they tend to argue and criticise each other?
- Can they work through problems together, or do things tend to break down into arguments?
- Do family members feel comfortable to speak openly with each other and say what they feel?

- Are the family members extremely anxious or worried about the patient or his welfare? For example, do they make statements like; 'I worry about him all the time', 'I do not know what to do', 'I cannot cope', 'I've been so depressed since he got ill'?

Does the family work together?

- Based on your observations of the family, you should be able to assess whether the members of a family work together; have a 'we' feeling.
- The members could be emotionally over-involved or they may be uninterested and have no involvement at all. Both can be counterproductive.
- Rituals, such as eating meals together or other joint family activities, strengthen the family and marital bonds.

How does the family cope?

Ask family members how they handled crises in the past. This indicates their ability to solve problems and will hint at how they will cope with the person with dementia. Ask each family member what his or her individual contribution was.

- Who took the initiative to solve the problem?
- How did they solve the problem?
- Were they able to effectively solve the problem or did it recur?
- Was the family confused and unable to solve the problem?
- Were they able to cope?

Source: Publication by Alzheimer's Disease International (ADI), Helping Carers to Care

D.

Proposals to Policy Makers in Greece

Proposals to Policy Makers in Greece

EPIONI weighing all the developments and taking into account the major social and national importance of the issue:

Calls for the immediate incorporation into the Greek legal order of Directive 1158/2019 of the European Parliament and of the Council of 20 June 2019.

- **The establishment of a care permit (article 6) for the employees-caregivers, which given the other shortcomings of our country should be set AT LEAST seven (7) days per year, with the possibility of extension up to 15 days, depending on the degree of disability of caregivers.**
- The establishment of flexible working arrangements for reasons of care (article 9). In particular, caregivers should be provided with flexible hours for the duration of the intensive care needs and the ability to change their form of employment from full-time to part-time (and vice versa), when required by the situation of the caregiver.

In addition, in the light of the requirements of the European Union and the shortcomings of the legislative framework of our country, we request the following legislative interventions:

- **The adopting by the Greek law of the concept of "caregiver"**, based on the elements of the invoked Directive.
- **The provision of financial assistance to a caregiver**, which will be determined according to the case, as the "caregivers" are forced to spend a lot of time and disproportionately large sums to cover the necessities for care, without state support.
- **The annulment of the last section of Article 25 §1 of Law 4440/2016**, where the rights of citizens belonging to the same family are unjustifiably limited. Specifically, the provision states: "*Five percent (5%) of the announced regular staff and personnel positions with a private law employment contract of indefinite duration, are covered by those having a child, brother or spouse, as well as by children of people with disabilities with a disability rate of sixty seven percent (67%) and above, due to serious mental and physical illnesses, as established by the health committees of KEPA. Exceptionally, concerning people with mental retardation or autism, protection takes effect at a disability rate of at least fifty percent (50%).* ***The exercise of the right of protection by a beneficiary of a family (parents, children, spouses, brothers) excludes the others.***"
- **The updating of Article 50 of Law 3528/2007** (Right to special leave) which provides: "*Employees who suffer or have a spouse or child suffering from a disease*

that requires regular blood transfusions or needs periodic treatment is entitled to paid leave of twenty two (22) working days per year. By a presidential decree, issued after a proposal of the Ministers of Interior, Public Administration and Decentralization and Health and Social Solidarity, the diseases of the previous paragraph are defined. 3. The leave of the previous paragraph is granted to employees who have children suffering from severe mental retardation or Down syndrome ", so as to include employees with responsibilities of caring for their family members (children, parents, spouses, siblings), who suffer from mental illness. Furthermore, this special permit should be instituted for employees of private sector legal entities.

- **The application of paragraph 2 of Article 53 of Law 3528/2007 (facilities of employees with family obligations)**, based on which a one-hour reduced schedule is provided for the parent who is unmarried or widowed or divorced or has a 67% disability and above, **and relatives of persons with disabilities or special care needs. The same provision should apply not only to civil servants, public corporations and local authorities but also to legal entities in the private sector.**
- **The transfer of the regulation for early retirement of Article 5 §4 of Law 3232/2004 to the public sector**, according to which *parents and siblings of unmarried people with a disability rate of 67% or more, who do not work and are not hospitalized at the expense of an insurance or other public institution, as well as spouses of invalids with a disability of 80% or more, if they have been married for at least ten years,* ***insured with main and auxiliary insurance institutions, under the Ministry of Labor and Social Security, establish a pension after completion of 7500 working days or 25 years of actual insurance, regardless of age and regardless of time of insurance.***
- **The recognition of 1-3 years of fictitious insurance** without redemption to the "caregivers" of people with chronic illness or disability.

Chief Ministers,

We believe that with the speed of the decisions that distinguishes you as well as with your specific weight, but also the declared sensitivity for the disabled - and therefore for their "caregivers", you will contribute to the drafting of a legal framework that will be a tool for the improvement of the quality of life of workers and people with needs, while at the same time will pave the way for their entry into the labor force, which our country so desperately needs in this critical juncture.

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www.learn4carers.eu

SEPTEMBER 2020

EPIONI
GREEK CARERS NETWORK

PEPSAEE
PanHellenic Association for the Psychosocial Rehabilitation & Work Re-Integration

Care Alliance Ireland

la compagnie des aidants

EURO CARERS
European Association Working for Carers

ΙΔΡΥΜΑ ΚΡΑΤΙΚΩΝ ΥΠΟΤΡΟΦΙΩΝ
ΙΚΥ

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