

InfoCARE: Supporting Informal Caregivers of People with Dementia

COLLECTION OF PEER-SUPPORT INITIATIVES AND PROGRAMMES IN SPAIN, AUSTRIA, TURKEY, GREECE AND DENMARK











InfoCARE – an Erasmus+ project

The InfoCARE project aims to support informal caregivers of people with dementia through providing different kinds of information- and learning materials, which can contribute to enhancing the lives of informal caregivers and their loved ones with dementia.

This e-book presents cases of peer-support initiatives and programmes in Spain, Greece, Turkey, Austria and Denmark. The case collection has been conducted by the InfoCARE consortium as part of Project Result 3. The cases that are presented here, are either peer-support initiatives that are related to dementia, or cases that have the potential to be adapted and applied to a dementia-related context.





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DENMARK





DENMARK: LÆR AT TACKLE (LEARN TO LIVE)

ABOUT LEARN TO LIVE: LÆR AT TACKLE (Learn to Live) is an evidence-based self-help course which has been developed on the basis of research and the Chronic Disease Self management Program, Stanford University. It consists of four basic courses offered to informal caregivers of adults (for example spouse, partner, parent or adult child) living with a long-term illness. The course focuses on informal caregivers and their self care, as well as how to live a good life despite an unpredictable daily life. The course equips you with useful tools that you can use to handle challenges such as stress, lacking surplus, guilty conscience etc. The course is also an opportunity for informal caregivers to meet peers and exchange experiences. The initiative is free and offered by 2 out of 3 municipalities in Denmark.

How can this be applicable to support groups for dementia caregivers?

The course could be introduced in Danish support groups for informal caregivers of people with dementia, as it could benefit this particular group.

Target group: Informal caregivers of adults living with a longterm illness.

Contact: Komiteen for Sundhedsoplysning

DENMARK: KRAEFTVAERKET

ABOUT KRAEFTVAERKET: A physical space at Rigshospitalet in Copenhagen, where young people (aged 15-29) with cancer can meet peers and hang out, have a talk with the youth coordinator or the youth ambassadors. Events and activities such as board games nights, different workshops, walk and talks, visiting theme parks etc. are also arranged by the youth coordinator and youth ambassadors. These ambassadors are nurses who have been educated to take on the role as youth ambassadors to help young people with cancer at Kraeftvaerket.

How can this be applicable to support groups for dementia caregivers?

This initiative could serve as inspiration towards creating initiatives that focus on young people who are informal caregivers to a person with dementia. Creating a physical space where young informal caregivers can meet with peers and youth coordinators and, for example, share their experiences and challenges of having a grandfather with dementia.

Target group: Young people with cancer (age 15-29)

Organisation: Kræftens Bekæmpelse (Danish Cancer Society)

Contact: Maiken Hjerming (Youth coordinator)

E-mail: https://www.rigshospitalet.dk/kraeftvaerket#







SPAIN

Visita Exposiciones y Actividades Crear y Aprende

Programa Alzheimer

El Programa Alzheimer del CCCB fue creado en octubre de 2010 por un grupo de trabajadoras del Centro con el objetivo de acercar el arte y la cultura a personas que sufren los primeros grados de la enfermedad, así como a sus cuidadores y familiares. Ofrece visitas adaptadas a las exposiciones del CCCB y un programa complementario de actividades

A lo largo de estos diez años de funcionamiento del programa, se ha demostrado el impacto positivo del programa tanto en el bienestar cognitivo y emocional de los participantes como en los cuidadores, familiares, las educadoras y la propia

La oferta de actividad se basa en las visitas adaptadas a las exposiciones. Cuando la visita a la exposición no es posible, se ofrecen actividades alternativas: un programa de cine en nuestro auditorio que incluye una selección de fragmentos clásicos de cine musical internacional y español o bien proyecciones de películas completas, una sesión sobre la historia de la Casa de Caritat basada en las fotografías de Brangulí o un breve itinerario para conocer el entorno del CCCB. Las actividades tienen lugar los lunes y se organizan bajo demanda. Para más información, hay que contactar con el Servicio Educativo (seducatiu@cccb.org)



SPAIN: PROGRAMA ALZHEIMER

Organisation: Centre de Cultura Contemporània de Barcelona

E-mail: info@cccb.org

More information (in Spanish): https://www.cccb.org/es/el-cccb/programa-alzheimer/231797
More information (in English): https://www.cccb.org/en/the-cccb/alzheimer-programme/231797





SPAIN: TARJETA CUIDADORA

ABOUT TARJETA CUIDADORA: The Caregiver Card aims to recognize the caregiver's work, accompany them, and facilitate their caregiving tasks in order to contribute to their well-being. It is available to those who care for sick, dependent, or disabled individuals or people with disabilities, or elderly people in the city of Barcelona. Also, caregivers in the immediate environment of the person being cared for and professional caregivers. This card offers personalized information and advice in person, online and by telephone; access to a free 24-hour emotional support telephone service; access to specific resources for caregivers in pharmacies, hospitals, sports activities, etc.; or access to a stable and proximity program of relational activities, among others.

How can this be applicable to support groups for dementia caregivers?

Ajuntament Barcelona's Caregiver Card is crucial for Dementia Caregivers Support Groups. This free card recognizes and supports caregivers, offering personalized resources, advice, emotional support, and access to diverse services. Monthly updates, free activities, and a virtual support space create a well-rounded model adaptable for Dementia Caregivers Support Groups.

Target group: Informal caregivers

Organisation: Ajuntament de Barcelona

Contact: Espacio Barcelona Cuida

Telephone: 34 934 132 121

More information (in Spanish): https://www.barcelona.cat/ciutatcuidadora/es/espacio-barcelona-

cuida/tarjetacuidadora

More information (in English): https://www.barcelona.cat/ciutatcuidadora/en/barcelona-care-

centre/carerscare

SPAIN: ESCUELA DE CUIDADORES





ABOUT ESCUELA DE CUIDADORES: Carers School is a space for transmitting the essential values of care in which the necessary tools are provided to facilitate the work of family carers and volunteers. The organization offers a monographic cycle of workshops in face-to-face or virtual format, lasting between 1.30 and 2 hours each, aimed at a minimum of 10 people and a maximum of 15, and led by experts in the different areas of the school (psychology, nursing, physiotherapy and social work). The training content of the school is structured around three areas: - Knowledge: technical content. Aimed at acquiring knowledge. - Being: principles and values. Focused on recognizing affection and motivation (emotions). - Doing: tools and skills. Aimed at facilitating resources and empowering caregivers.

How can this be applicable to support groups for dementia caregivers?

Carers School provides crucial support for Dementia Caregivers Support Groups. This virtual workshop, led by experts, equips non-professional carers with essential knowledge, techniques, and skills for advanced illness or end-of-life care. The flexible format, available in-person and virtually, enhances caregivers' capabilities, ensuring adaptability for inclusion in Dementia Caregivers Support Groups.

Target group: Informal Caregivers

Organisation: Fundación "la Caixa"

Contact: Fundación "la Caixa"

E-mail: info@escueladecuidadores.lacaixa.org

More information (in Spanish): https://fundacionlacaixa.org/es/atencion-integral-personas-enfermedades-avanzadas-cuidadores

More information (in English): https://lacaixafoundation.org/en/



GREECE

ΕΤΑΙΡΕΙΑ ΝΟΣΟΥ ALZHEIMER ΚΑΙ ΣΥΓΓΕΝΩΝ ΔΙΑΤΑΡΑΧΩΝ



eer Support Workers is an Innovative force in idvocacy in dementia care

Read more >





GREECE: PEER-SUPPORT WORKERS AS AN INNOVATIVE FORCE IN ADVOCACY IN DEMENTIA CARE

ABOUT PSW-PIA: Peer Support Workers (PSW) as an Innovative Force in Advocacy in Dementia Care (PIA) project aimed to create sustainable and competency-enhancing services for people with dementia by finding new ways to involve former as well as current caregivers in dementia services and therefore, provide their valuable perspective in dementia care and daily practice. The project aimed to reduce the stigma associated with dementia, therefore allow dementia diagnosed people to seek help at an early stage.

How can this be applicable to support groups for dementia caregivers?

This project organized dementia caregivers support groups and it has also developed materials on how to create peer support workers groups and activities

Target group: Informal caregivers of adults living with dementia

Organisations: Alzheimer Hellas (Greece), KBT Vocational school (Norway), Habilitas (Romania), Anziani e Non Solo (Italy), ASOCIATIA AFECT (Romania)

Contact: Dr. Marianna Tsatali, Alzheimer Hellas

E-mail: tsolakim1@gmail.com

More information (in English): https://piaproject.eu/

GREECE: INTERVENTIONS FOR CAREGIVERS OF PEOPLE WITH DEMENTIA IN GREECE

ABOUT INTERVENTIONS FOR CAREGIVERS OF PEOPLE WITH DEMENTIA IN GREECE: Panhellenic Federation of Alzheimer's Disease and Related Disorders (PFADRD) is a non-profit organisation that was founded in 2007. The Panhellenic Federation consists of 45 linked Associations of Alzheimer's disease all over Greece. PFADRD offers different interventions for caregivers of people with dementia. The supportive interventions have been developed in various forms, such as face to face and online form, in order to meet the needs of the population of the caregivers. The interventions provided to caregivers are (a) psycho-educational group, (b), online psychoeducational group, (c) family support intervention, (d)psychological support group, (e) support group using literature entitled "Listen to my story", (f) "theater of the oppressed", (g) relaxation intervention, (h) grief support group, and (i) community outreach: intervention for children entitled "Who I am grandpa?" and radio program "All about dementia".

How can this be applicable to support groups for dementia caregivers?

These interventions are offered to formal and informal caregivers of people with dementia. In some interventions like the "Psychological support group", caregivers learn how to support each other through peer support groups.

Target group: Informal caregivers of adults living with dementia

Organisation: Panhellenic Federation of Alzheimer's Disease and Related Disorders

Contact: Alzheimer Federation Info

E-mail: <u>info@alzheimer-federation.gr</u>
More information (In Greek): https://www.alzheimer-hellas.gr/index.php/el/services/kentro-frontidas





ΤΜΗΜΑ ΠΕΡΙΘΑΛΠΟΝΤΟΝ-ΥΠΟΣΤΗΡΙΞΗ ΟΙΚΟΓΕΝΕΙΑΣ

Το Τμήμα Περιθαλπόντων παρέχει υποστηρικτικές, εκπαιδευτικές και συμβουλευτικές υπηρεσίες στους περιθάλποντες και στις οικογένειες των ατόμων με άνοια. Στόχος αυτών των παρεμβάσεων είναι η βελτίωση τόσο της παρεγόμενης φροντίδας όσο και της







GREECE: SUPPORTING INFORMAL CARERS: A WHOLE-FAMILY AND LIFE COURSE APPROACH (S.IN.CA.L.A)

ABOUT S.IN.CA.L.A: The main objectives of this project were: (1) To develop and test a pedagogical method based on narration, adapted to different EU country contexts, targeting households caring for older family members. (2) To provide informal carers with an opportunity to participate in an intervention designed particularly for them. (3) To make available to educators and professionals working with family carers the S.IN.CA.L.A E-Learning course (MOOC).

How can this be applicable to support groups for dementia caregivers?

This intervention and this course included guidelines on how to support caregivers and how to organise support groups.

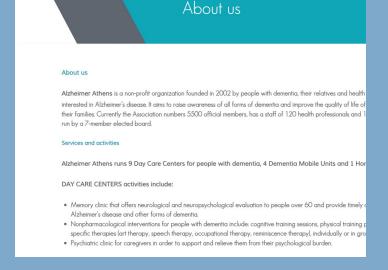
Target group: Formal and informal caregivers, as well as health care professionals

Organisations: Women's Support and Information Centre (WSIC) (Estonia); Greek Association of Alzheimer's Disease and Related Disorders (Alzheimer Hellas) (Greece); Union of Women Associations of Heraklion (Greece); Anziani e non solo (Italy); CASO50+ Centro de Atendimento e Servicos 50+, Associacao (Portugal); Spomincica, Alzheimer Slovenija (Slovenia); TARTU ULIKOOL -University of Tartu (UT)

Contact: Greek Association of Alzheimer's Disease and Related Disorders (Alzheimer Hellas)

E-mail: mkozori@yahoo.com





GREECE: SCHOOLS FOR CAREGIVERS OF PEOPLE WITH DEMENTIA AND ALZHEIMER DISEASE

ABOUT SCHOOLS FOR CAREGIVERS OF PEOPLE WITH DEMENTIA AND ALZHEIMER DISEASE: The Alzheimer's Society of Athens has been actively supporting people with dementia, their families and caregivers for years. Recognizing the burden that caregivers of people with dementia bear - both physical and psychological - and the practical issues that arise from caregiving, the Alzheimer's Society of Athens has dedicated a large part of its activities to psychological support and caregiver education. Thus, the Alzheimer's Society of Athens organized the last years the "School for caregivers of people with dementia and Alzheimer's disease". It is a program that includes several informative and educational lectures for caregivers. Professionals from all around Greece give a presentation to a group of caregivers and they try also to support them through the group session and create a bones between participants. The meetings are of two-hour duration, and they are free of charge.

How can this be applicable to support groups for dementia caregivers?

These schools are helpful for caregivers, and they learn on how to support themselves and others by participating in support groups

Target group: Informal caregivers of adults living with dementia

Organisation: Athens Alzheimer Association

Contact: Athens Alzheimer Association

E-mail: <u>info@alzheimerathens.gr</u>

More information (In Greek): https://alzheimerathens.gr/%CF%83%CF%83%CF%87%CE%BF%CE%BB%CE%B5%CE%B9%CE%BF%CE%B9%CE%BB/CE%B9%CE%BD/



TURKEY



TURKEY: LIVE AN ACTIVE AGE, AVOID ALZHEIMER'S

ABOUT LIVE AN ACTIVE AGE, AVOID ALZHEIMER'S: Turkey Alzheimer Association's Denizli branch prioritizes enhancing the lives of dementia caregivers. Services include psychological counseling, support group sessions, and socio-cultural activities for emotional well-being. Individual and group psychotherapies target specific needs, while educational workshops offer up-to-date information on Alzheimer's. Social media keeps the community informed. The association also hosts open-to-the-public activities, promoting an active lifestyle. From folk dance and theater to chess and rhythmic sessions, participants engage in intellectually stimulating and creative pursuits. Collaborations with education centers and volunteers bring stone painting and handicraft activities. The diverse program aims to create a supportive community, fostering unity through excursions, picnics, and annual events.

How can this be applicable to support groups for dementia caregivers?

The Denizli Alzheimer Association's offerings, such as psychological counseling, support group sessions, and diverse socio-cultural activities like theater and music courses, can be directly applied to Dementia Caregivers Support Groups. These activities contribute to emotional well-being, offer creative outlets, and foster a sense of community among caregivers.

Target group: Azheimer Patients Family member and general elderly people

Organisation: Türkiye Alzheimer Derneği Denizli

Contact: Hatice Hülya ERYILMAZ

E-mail: <u>denizlialzheimer20@hotmail.com</u>

More information (In Turkish): https://www.alzheimerdernegi.org.tr/sube-ve-temsilcilikler/denizli-subesi-ethiplikleri/

etkinlikleri/

More information (in English): https://www.alzheimerdernegi.org.tr/english/



TURKEY: TEA TIME MEETINGS

ABOUT TEA TIME MEETINGS: The Alzheimer Tea Time Meetings, hosted at Alzheimer Gündüz Bakımevi Yaşamevi, constitute a targeted support program for dementia caregivers. This initiative spans monthly sessions from November 2023 to June 2024, featuring expert-led discussions on topics such as disease fundamentals, legal considerations, mindfulness, and gerontological care. The structured meetings operate within a secure environment, offering psychosocial aid, mental rehabilitation, and valuable respite for caregivers, ultimately enhancing the overall well-being of those caring for individuals with dementia.

How can this be applicable to support groups for dementia caregivers

The program's monthly structure, integrating psychosocial support and caregiver respite, directly suits the needs of Dementia Caregivers Support Groups. These sessions serve as an exemplary model for support group activities, providing essential insights, fostering community, and offering practical guidance, crucial for caregivers managing the complexities of dementia care throughout the extended program duration.

Target group: Dementia Caregivers

Organisation: Gerontolojik Hizmetler Birimi- Sosyal Destek Hizmetleri Müdürlüğü- Şişli Belediyesi and Turkey Alzheimer Association

Contact: Gerontologist Tuğçe TINGIR

E-mail: sosyal.destek@sisli.bel.t

More information (In Turkish): https://www.sisli.bel.tr/haberler/alzheimer-gunduz-yasam-evi-cay-saati-program and https://www.sisli.bel.tr/hizmet-merkezi/alzheimer-gunduz-yasam-evi and https://www.alzheimerdernegi.org.tr/bilgilendirme-toplantisi/



AUSTRIA





AUSTRIA: FIT@CARE

ABOUT FIT@CARE:Getting fit in care and assistance. Person-centered training for relatives of people with dementia in 8 modules.

How can this be applicable to support groups for dementia caregivers?

The project aims to teach skills to caregivers of dementia patients within 8 comprehensive modules, that include a lot of important information that will guide them. The modules are focused on disease patterns and therapies, communication and conflict management, crisis intervention, shaping relationships and changing roles, dealing with loss and grief as well as social and legal issues. Participants also have the chance to bring up their own topics in one of the modules.

Target group: Caring Relatives of Dementia Patients

Organisation: Alzheimer Austria

Contact: Antonia Croy

E-mail: antonia.croy@chello.at

More information (In German): https://www.alzheimer-selbsthilfe.at/wp-content/uploads/2022/02/fit@care-mit-Logos.pdf





AUSTRIA: EINE BIBLIOTHEK FÜR ALLE – DIE DEMENZFREUNDLICHE BIBLIOTHEK WIENER NEUSTADT

ABOUT DIE DEMENZFREUNDLICHE BIBLIOTHEK WIENER NEUSTADT: The project focuses on health literacy and social participation of people with dementia and family caregivers of people with dementia. It is designed as a participatory practical project in order to take into account aspects of needs orientation and sustainability from the

How can this be applicable to support groups for dementia caregivers?

The project can support Dementia Caregivers Support Groups by promoting health literacy, fostering social participation, adopting a participatory approach, prioritizing sustainability, and engaging with the community to raise awareness about dementia and its impact on individuals and families.

Target group: General public, especially older citizens, employees from the library, citizen service center and city museum, people with cognitive impairment/dementia, caring relatives

Organisation: Fachhochschule Wiener Neustadt in cooperation with others

Contact: Dr.in phil. Verena C. Tatzer, MSc

E-mail: <u>verena.tatzer@fhwn.ac.at</u>

More information (In German):

https://www.fhwn.ac.at/hochschule/infrastruktur/bibliothek/dembib#projektbeschreibung

More information (in English): https://www.fhwn.ac.at/en/













InfoCARE Consortium













@infocareproject www.infocare.me

infocare.erasmusproject@gmail.com



