CARE4DEM

Dementia Caregivers Support

Web-based mutual aid groups model

Implementation Guide

Intellectual Output 2



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Programme
CARE4DEM – Dementia Caregivers Support

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01

Care4Dem - Dementia Caregivers Support

Care4Dem - Dementia Caregivers Support

1.1. About Care4Dem Project

Care4Dem – Dementia Caregivers Support project is a three-year project funded by the **Erasmus+ Programme of the European Union** and establishes a partnership of six non-profit organisations, 5 national organisations from Italy, Portugal, Romania and Spain, and one European wide organisation.

This project aims to develop a new and innovative model of mutual aid groups which promotes caregivers' involvement by introducing web-based tools and integrating it with other type of interventions, in order to enhance caregivers' satisfaction with care and reduce burnout.

It also intends to expand the professional development of mutual aid groups' facilitators by creating a network for mutual and peer learning cross Europe.

Care4Dem project goals are:

- To design and to develop a new and innovative web-based model of mutual aid groups for informal caregivers of people with dementia, including learning materials for caregivers;
- To identify the suitable profile and competences to perform the facilitator role of mutual aid groups;
- To develop a multimedia training course to enhance the competences of mutual aid groups' facilitators;
- To pilot a web-based mutual aid group model;
- To create a network of professionals across Europe who work towards better support of informal caregivers of people with dementia.

This project began in September 2017 and last until August 2020.

1.2. Why the Care4Dem model?

Demographic ageing in Europe gives rise to a growing incidence of age-related conditions, an increasing demand for care and a serious sustainability test for our social and health-care systems. According to research, informal carers provide over **80% of all care in Europe**, with women providing approximately two-thirds of care mainly as daughters (in law) and wives/partners. Estimates suggest that the economic value of unpaid informal care in the EU – as a percentage of the overall cost of formal Long-Term Care provision – ranges from 50 to 90 %. Caring for someone with dementia raise particularly acute challenges. However, informal carers' contribution is poorly recognised, their needs overlooked, and they are not sufficiently supported by the formal services that are available.

Social, psychological and educational interventions are among the best strategies for informal carers to manage the pressure of care and get supported in their caring role. Some European governments have put in place various supports, mainly financial measures and in-kind services, to help informal carers compensate for their economic loss and to allow them to reconcile care and work. Nevertheless, ***these***



solutions seem to cover their needs only partially. Furthermore, the COVID-19 pandemic has exacerbated the pre-existing difficulties faced by informal carers, increasing the risks to their physical and mental health and well-being. Carers remains the last safety line for vulnerable people in times of crisis, when confinement measures, as well as the de-prioritisation of non-essential treatments, is exacerbating their burden and isolation.

Evidence shows that informal carers have a wide range of social and care needs: recognition, psychological support, information, advice and counselling about care, caring and care-life balance, training and recognition of skills, health prevention, respite, participation in the labour market and in the community and development of their rights. ***The preventive aspects of well-trained and well-supported informal carers*** in avoiding or delaying hospital admission and long-term institutional care are well documented. ***Mutual Aid Groups, because they create a secure space for peer support***, can efficiently provide some of the support needed, complementing necessary public support.

Recognising, developing and validating the numerous– sometimes very technical - skills gained by informal carers while performing their caregiving tasks also offers great potential to improve the quality of life of carers and their care recipients, but also to contribute to their inclusion in society. Therefore, ***offering training opportunity for carers*** is key to empower them and invite them to contribute to better supporting all carers in the community. Furthermore, such training opportunities might encourage them to build on their skills to engage in a personalised training pathway and remain active in the labour market, should they wish so.

Against this back drop, and at a time when new technologies bring transformation to our entire society, there is clear evidence of the added-value that ICT can bring to informal caring, to the benefit of both informal carers and people cared for. ICT-solutions are accessible to the carers who cannot take part in face-to-face interventions, due to their lack of availability or the lack of opportunities in their areas. Accessible ICT-based solutions might also help develop ICT literacy among those concerned by the digital gap, provided they are accompanied to use them.

Therefore, the present model of online Mutual Support Group is available for all professional and experienced carers willing to use this innovative approach and contribute to better support carers in their community. It is hoped that it will be used widely.

Yet, given the scope of the CARE4DEM project, it is far from addressing all carers' needs, and could be usefully complemented, and embedded in a range of comprehensive support services. As such, its limits are an acute illustration of the need for a more comprehensive strategy for carers[1] to be developed at the local, national and EU level, for carer-friendly societies.

[1] See Eurocarers' 10 steps for care-friendly societies across Europe: https://eurocarers.org/strategy/



02

Introduction to the Implementation Guide

Introduction to the Implementation Guide

The effective implementation of the Care4Dem model by many organisations, professionals and community can be supported by a step-by-step approach. This guide includes implementation guidelines regarding the Care4Dem model to support informal caregivers of people with dementia with the purpose of providing details on the process, different phases and activities to carry out in order to reach informal caregivers of people with dementia through online support. The steps were followed by **4 project partners** in **3 different countries** (Italy, Portugal and Romania), contributing to:

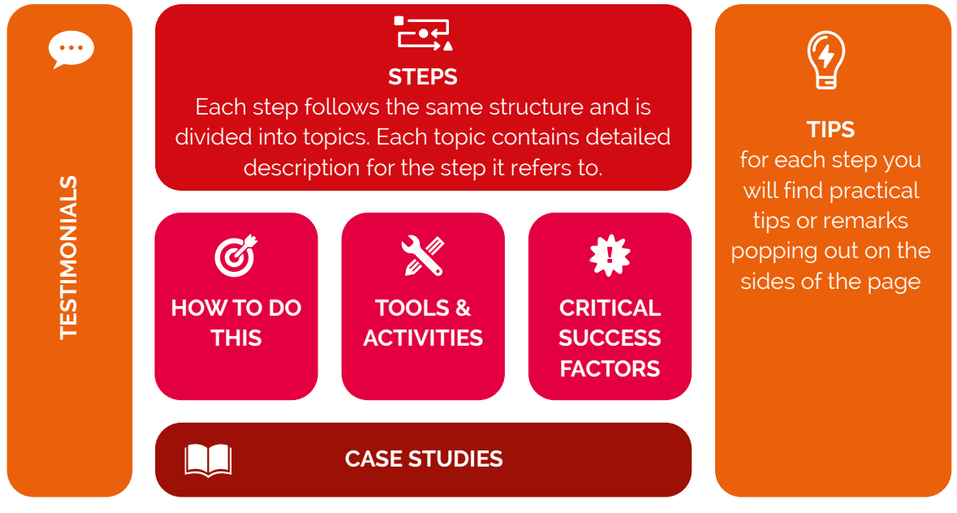
- **4** pilot training courses
- **39** facilitators trained
- **7** online support groups delivered
- **42** informal carers participated

This implementation guide targets anyone who is willing to implement online support to informal caregivers, by using the methodology of mutual support groups. It is divided through different steps to implement the Care4Dem model, based on the approach piloted by project partners:



How are the steps structured?

Each chapter of this guide refers to a step. In each of the steps, there is a general overview followed by clear details on 'how to' deliver the related step, together with tools and activities, and critical success factors; case studies, testimonials from participants in the pilots and tips from project partners are introduced.



The use of the process map and its corresponding steps is not a mandatory aspect of the implementation of a web-based mutual aid group. Smaller organisations/ individuals might use the material in a more organic way, picking what they consider as useful for them to develop their own programme of mutual aid groups. The structure foresees to support systematization, to open room for standardization and quality, and to foster improvement in terms of approach, methodology, and features. The core aspects of each step are highlighted below:



Additional support and guidance for a comprehensive view of the Care4Dem model are available through Care4DEm intellectual outputs and reports. Check which intellectual outputs supports best each step:

	Recruitment of Facilitators	Training of Facilitators	Scout of Informal Caregivers	Delivery of Online Support	Assessment & Evaluation
Web-based mutual aid groups of informal carers: an evidence review	✓	✓		✓	✓
Facilitators' profile	✓				✓
Facilitators' competences tool	✓	✓			✓
Care4Dem Training Handbook		✓			✓
Web-based support groups model - Implementation Guide			✓	✓	✓

✓ Good support ✓ Medium support

You can get more information about all the intellectual outputs from: **https://eurocarers.org/care4dem/innovative-model/.**



03

Care4Dem model to support informal caregivers of people with dementia using web-based mutual aid groups

Peer-support can be defined as the process of giving and receiving nonprofessional, nonclinical assistance from individuals with similar conditions or circumstances. A peer support group (or mutual-aid group – MAG) happens when people experiencing similar conditions, voluntarily gather together to receive support and provide support by sharing knowledge, experiences, coping strategies, and offering understanding. There is evidence that participating in a MAG has positive impact in mood, self-efficacy, and burden...

(Tracy, 2016)

3.1. Recruitment of facilitators

"experience (in caring and in participating to support groups), motivation, and soft skills (communication, empathy, sensitivity) seem to be of paramount importance"

The dictionary describes "facilitate" as a way to "make something easier". A facilitator is a person who makes group discussion easier.

The facilitator follows the dynamic of the group. This is done by maintaining rules of the group, managing interruptions, listening attentively and starting/stopping groups on time. The facilitator is there to make all participants feel welcome and comfortable and to help the discussion to remain healthy and adequate.

If you are willing to launch a mutual support group for caregivers, the first step is to identify and select the appropriate person to facilitate the group. The screening process you use is key as the way you assure potential candidates can fit the role.

Care4Dem model envisages an approach of **co-facilitation***. Each group shall involve 2 facilitators:

1. A former carer or a "senior" carer (preferably, who have participated in other support group) strategic for identity and sustainability of the group
2. A professional (psychologist, educator, social worker…) core for stabilising the group format and functioning

The recruitment and selection of such persons require the definition and implementation of a clear process.

***Tip**

Involving 2 facilitators for each group, a professional and an experienced caregiver, allows to balance the skills in favour of a more complete facilitation. However, it is important to allow the 2 facilitators time to communicate, coordinate in the facilitation and get to know each other. To this end, you could suggest that they contact each other privately 15 minutes before each session and to spent 15 minutes after each session to discuss the progress and support each other if they need.

How to do this

You might already have a pool of potential candidates within your organisation (staff members) and services (other activities for informal carers). For those who are starting a journey in supporting informal carers, additional tasks might be needed.

1. Set up the profile of your facilitator
2. **Announce the opening of a position[C1]**
3. Communicate the expected role and responsibilities
4. Screen potential candidates
5. **Identify the expectations of the facilitators[T1]**
6. Analyse the results
7. Create categories of selected facilitators

Tools & Activities

The Care4Dem **facilitators' profile and competences tool** can support you in the process of setting the profile required to implement a mutual support group. In this resource you may find details concerning the knowledge and skills needed from a person. You can also use the competences' tool which is available online and the results are provided to each person directly. You can use it yourself in the recruitment process.

As a common criterion, Care4Dem model suggests:

1. For the senior carer: have participated in other support groups.
2. For the **professional[T2]**: background in health and social fields, such as educator, gerontologist, psychologist, social worker.

[C1] Case Study 1

CASO50+, one of the Portuguese partners, chose to disseminate the opening of a position to be facilitator as a volunteer basis. It used two strategies: social networks and e-mail. 3 Facebook posts were made highlighting the relevance of the project and inviting people to participate. The same was done through CASO50+ mailing list. The selection of contacts considered those matching the criteria of the target profile: professionals working in the field of health and social care. A total of 21 people were interested in the programme.

[T1] Testimonial

"Initially the expectations of the future sessions developments were very centered on me, making me think more about "and if this happens how do I manage it?", "If no one speaks, what will I say?", "If they quarrel among themselves how will I sit the discussion?", "And if people don't want to participate anymore, why don't I make the session stimulating?" rather than the fact that the protagonist was not me but the caregivers. And so it was."

(Italian Facilitator)

[T2] Testimonial

"It's wonderful to be able to help other people. When from someone's face you understand that you have done him "any good", I feel a great joy internally. It would be wonderful to have a profession that could give me continuous happiness".

(Italian Facilitator)

The **roles and responsibilities** of both facilitators need to be clearly defined, either as a starting point for the selection of the person, either to create a good atmosphere between the carer and the professional. You can use the tools at the end of this guide to support this action: they are to be adapted to your specific context and programme.

By setting categories of facilitators, the task of attributing persons and groups will be easier in terms of matching.

In brief:

Facilitators' profile and competences tool *(check detailed output)*

Tool#1 Responsibilities of Facilitators

Tool#2 Roles fo Facilitators

Tool#3 Rules for Facilitators

Critical Success Factors

- Clear form of contribution requested to facilitators (e.g., volunteering or financial compensation)
- Engagement with former carers and persuade them to be facilitators
- Clear schedule of the commitment requested to facilitators
- Highlight the benefits of participating in the training

Case Study 2

Training programmes for facilitators of peer-support groups are relatively common in Italy, however e-facilitation is innovative and the Italian partner Anziani e Non Solo was not aware of similar programmes offered in the country.

Facilitators were recruited through the launch, back in August 2019, of a call for participants disseminated:

- via ANS Facebook
- via ANS mailing-list
- via a Whatsapp group of informal carers who are users of ANS services.

The call was offering the opportunity to take part to a free training course for facilitators of online MAGs and it was addressed both to professionals in the social and health-care sector and to informal carers.



Figure 1- Card to promote the training

Participants were asked to provide a short bios and to illustrate their experiences with MAGs and motivation to take part of the training. This information might be the basis for a selection in case the number of participants is higher than places available.

The training was advertised as blended, including an internship phase (i.e. the facilitation of online sessions with the supervision of expert facilitators), for an overall duration of three months. This launch reached 9 persons, while only 6 did kept on going: 4 professionals (among which 1 was also a carer) and 2 informal carers.



Figure 2- Process of recruitment

The Italian partner didn't encounter any major challenge in recruitment, however it had to accommodate the needs of the participants who were also carers: one couldn't leave her mother to attend the face-to-face training, so she followed that remotely via Skype. Another one could not leave her job to attend the full face-to-face training, so she attended only part of it and then one of the trainers caught up with her in a later stage.

3.2. Training of facilitators

"facilitators are required to have followed a training"

T1 Testimonial

"Seeing so many persons who wish to implement an online mutual support group without any remuneration has shown us the level of solidarity between informal caregivers and social practitioners" (CARE4DEM training coordinator, Romania)

T2 Testimonial

"Whilst the Care4Dem model is designed to be conducted online, a Face 2 Face training for facilitators wherever possible is recommended. This allows for role-play between facilitators and an opportunity for facilitators to collect feedback in real-time quickly without the interference of technological complexities". (Participant of staff training, UK)

***Tip**

During face-to-face training it is important to deal with any doubts about the issues covered in the e-learning part and to provide participants moments of discussion, both with the trainer and with each other.

The facilitation of an online support group like the Care4Dem model implies the mobilization or the development of some competences, especially related with communication, empathy, or online facilitation of groups. While one may possess the necessary skills, others, like informal carers, may have been acquiring such competences through the experience of caring for someone with dementia and participating in face-to-face support groups and forums. **Anyone can express the willingness**[T1] to take a more active role towards informal carers and implement the Care4Dem model.

The blended training course for Care4Dem Facilitators offers the possibility to recognise and develop skills. fosters commitment to support informal carers and can help strengthen their own capacity[T2]***.*** This is of special relevance for senior carers. A blended approach in training is a **mix of online and face-to-face sessions*.**

As a standard, both facilitators of Care4Dem online support groups shall follow a dedicated training, such as the one developed as Intellectual Output 4 of the Care4dem project, which focuses on the following topics:

a. Introduction to Care4dem model

b. Basics of dementia

c. Informal carer

d. Introduction to MAGs

e. Facilitation of MAGs

f. Communication skills

g. E-facilitation

h. Online mutual aid groups – the Care4dem model

The Care4Dem training for facilitators was developed based on the facilitators' competence profile.

How to do this

1. Evaluate the learning needs of facilitators based on their completion of the self-evaluation tool
2. **Draw the training programme which addresses the work requirements**[T3]
3. Decide on the format, duration and learning modules to use
4. Identify suitable trainers
5. **Deliver the training***
6. Assess the results of the training

Tools & Activities

The Care4Dem ***training handbook*** offers you a detailed description of how to implement and use the Care4Dem learning materials. It provides a course curriculum based on the main competences of the facilitators' profile and a set of learning plans and activities tested and implemented during the pilots in Care4Dem project. The main added value is that you can organise and tailor the training programme according to the facilitators' profile you have set for your own online support group programme. To get the full Care4Dem training handbook, go to: **https://eurocarers.org/care4dem/for-facilitators/.**

T3 Testimonial

"The preparation course was well structured and provided the right tools to develop attention towards caregivers, prepare them for constructive participation in the group and helped to identify possible problems or difficulties that can sometimes arise in these contexts." (Trainee, Italy)

***Tip**

It has proved essential to offer practical opportunities for using ICT (PC, Skype and devices) and to carry out MAG session simulation activities to practice e-facilitation. This is the key aspect of online MAGs and it will make the difference on promoting facilitators' skills, by facing possible difficulties using ICT, but also to identify themselves with a caregiver who wants to offer and receive support through an online MAG. Be sure that you have the adequate equipment and a good internet connection.

T4 Testimonial

"The face-to-face sessions of the facilitators training proved to be crucial moments to clarify some topics, especially the role of the facilitator in online mutual aid groups. The debate among participants also prove to be very enriching" (Trainee, Portugal).

C3 Case Study 3

The Portuguese partner Aproximar delivered the training following the full course curriculum proposed and a blended training approach. Learners were 9 professionals from social and healthcare fields, most working in non-profit organisations as social workers or psychologists, 3 of them had experiencing in facilitating mutual aid groups, even not all for caregivers.

The training course for facilitators delivered by Aproximar combined online contents (e-learning multimedia modules and quizzes) before face-to-face activities. There were no synchronous sessions but at the e-learning platform, the learners could get access to main information on theoretical background of each module, having spent an average of 6 hours. The face-to-face sessions covered practical exercises about how to facilitate a support group using online tools, especially by simulation exercises and some problem-solving activities in group. It was relevant to add additional synchronous group meetings to assess the feasibility of online meetings, due to technical characteristics from being all participants in the same room.

The experience of offering online contents beforehand and intensive 2-day-training showed to be effective, counting on the availability of professionals to leave their working spaces to come to training. The Portuguese learners mentioned that the exchange of experiences between participants and their valuable experience and background were the most added value.

As part of the Care4Dem pilot, project partners have ***introduced the facilitators' competences tool (a self-assessment questionnaire) to identify the learning needs and assess the efficacy of training,*** by a comparing pre and post results. This tool and its results can provide you with information on the knowledge and skills which need to be developed within the training and make the training course more individualised and tailored to each specific group of learners.

In brief:

Facilitators' profile and competences tool

(check detailed output)

Care4Dem Training Handbook

(check detailed output)

Critical Success Factors

1. Clear identification of the skills[T4] needed
2. Selection of suitable trainer
3. Balance between theory and practice
4. Easiness of using a blended approach[C3]

Case Study 4

In Romania, the learning programme was received with attentiveness by the target group registering more than 20 interested persons. All those who registered to participate on the training had to start their learning path with the CARE4DEM Competence assessment tool to identify their strengths but also their weaknesses as a facilitator.

The pilot course was delivered in a blended learning format, meaning that participants had access to the training modules on an online environment (a Learning Management System - LMS), and then, met face-to-face with the trainers during 3 days to consolidate the information obtained through the online sessions. They had the opportunity of self-learning by accessing the presentations, quizzes and exercises at any time of their availability. The recommendation of the regional partner for the trainees was to complete the online modules before attending the class sessions so they can explore together the topics that were not fully understood.

The participants were receptive and curious regarding the subject and they were looking forward to implementing their own mutual aid groups as a facilitator. The training course, as the participants have evaluated, had a balanced use of theoretical and practical learning. We have also included a simulation of a support group, to prepare the future facilitators for any unforeseen challenges and to let them know what to expect. Another objective of the class sessions was to encourage them to collaborate and develop a teamwork spirit since they had to co-facilitate groups together.

The assessment tool has been used also to test the users' competence after having completed the learning programme to visualize the progress made.

Organizing the training pilot

- analyzing the profile of the persons who registered to attend the course
- confirmation of participation and the acknowledgment of a mutual aid group implementation after the completion of the training

Access on the online platfom

- providing to participants the credentials to access the LMS platform
- sharing a short user guide for LMS, for the CARE4DEM platform and for Skype
- support the users to access the modules and follow all the available materials (presentations, quizzes, etc.)

Class sessions

- organize the class session plans
- adapt the activities on the needs of the group
- organize a simulation of an online mutual support group
- provide support for the implementation of the mutual aid group

Evaluation

- quality of the training survey
- training satisfaction survey
- trainees' evaluation

3.3. Scout of informal caregivers

"Recruitment strategies should take into account the specificities of informal carers"

The use of mutual aid groups is effective for informal carers in **relieving their burden**[T1]. The scouting and retention of such participants shall take into consideration their unique profile and characteristics, such as ICT-literacy or readiness for exchanging with peers.

The channels used to reach these target group may differ if one is already providing services to carers or is entering this field. **It is important to identify dedicated promotion channels, in order to make sure that information reach the right people***. One may find beneficial to get closer cooperation with organizations of carers or local public policy entities (such as municipalities). Special attention should be focusing on reaching the target population living in more isolated/ not urban areas.

While **informing about the programme**[T2] of online mutual aid groups, it is important to recognize the difficulties of the informal caregiver to participate in such groups and to acknowledge that there might be drop-outs or inconstant participation and this shall not be perceived as an extra-task for the carer. **Adherence to the group is solely voluntary****.

The scout of caregivers shall consider the integrative services provided to carers and plan it in a way to embed online mutual aid groups with other activities, even considering both virtual and physical support. Additionally, you need to ensure the access to ICT training opportunities, either integrated in your own programme as a previous step or by making use of opportunities offered at local level.

[T1] Testimonial

"Giving hope to someone who is in a difficult situation can mean everything at a certain moment". (CARE4DEM training coordinator, Romania)

***Tip**

To encourage greater involvement in groups and the awareness of the role they play, during the scouting process it is important to clarify to informal caregivers what is an informal carer, explaining it in simple terms. So that it is easier for them to understand what it means, what are the challenges they could face being caregivers, helping them to identify themselves in the role and to reflect on what they could do to get better their daily life and the other caregivers' daily life.

[T2] Testimonial

"At the beginning, some were sceptical about the project (some said that they had participated in other initiatives but had not benefited from it); others had a face that reveal me "fear" "insecurity". Now, in my opinion, they have become more confident and know that they are not alone in facing health problems. There are so many informal carers out there working hard every day!" (Facilitator, Italy)

****Tip**

Provide simple and clear information and not all at once since it might be overwhelming. Present the benefits of a support group.

How to do this

1. Check the inclusion criteria for the groups
2. Communicate the launch of the group
3. Setup a recruitment protocol
4. Contact potential candidates
5. Inform selected candidates of their inclusion in the programme
6. Make individual calls with participants
7. Distribute participants by groups

Tools & Activities

Anyone who is an informal carer of a person with dementia (even lacking a formal diagnosis) can be included in Care4Dem online mutual aid groups, regardless of type of bonding or level of care provided (primary, secondary).

The ***Care4Dem inclusion criteria*** is a starting point for the definition of the specific target group. You may consider adapting it to your own context or to launch specific online mutual aid groups for specific criteria, for instance, spouses, children, etc.

The second step for scouting participants is to **spread the information about the existence of the online support group**[C5], where to know more about it and how to register as participant. Information about the support group can be disseminated by means of electronic communication (e.g. e-mail, websites, newsletter), face-to-face (e.g. seminars, recommendation by family doctors), but also **resorting in printed materials (e.g. leaflets, posters) placed in strategic places*****.

[C5] Case Study 1

The scouting of caregivers was a crucial step in the piloting of the online group in Romania. All the facilitators who have completed the training programme were involved in the recruitment campaign through different methods. They made use of a set of posters designed by EaSI (the Romanian partner) which were exhibited in the social and medical institutions. Another way to promote the support group was the National Alzheimer Conference, which offered a great opportunity to present the project and ask the support of a high number of professionals who work directly with informal carers. A more direct approach of scouting has been conducted on social media since the informal carers already established a community to discuss the difficulties they face within the caring process. The proposal to participate in the CARE4DEM online group has been received with enthusiasm and 42 carers expressed their interest in participation.

***Tip**

Posting flyers and posters on strategic local spots in the community (e.g. drugstores, libraries, coffee shops, hairdressers, etc.) may be a way to reach more people.

T3 Testimonial

"In the large group of which I was co-facilitator, the will clearly emerged in each participant to be present to make a difference, to create a new potential and a new point of view that offers the opening of a better quality of daily life for himself and for others".

(Facilitator, Italy)

The registration form shall collect only the necessary information as it is the first expression of interest. It is important that after registration, you can get to know your participants through individual conversations and assess their ICT skills.

The admission process shall cover individual contacts through email and phone calls. You can get templates for the texts in Care4Dem tools available at the end of this implementation guide.

In brief:

Tool#4 Inclusion criteria

Tool#5 Poster for recruitment

Tool#6 Registration form

Tool#7 Admission scripts

Critical Success Factors T3

1	Clear and appealing message
1	Use of the appropriate channels of communication
1	Collaboration with family doctors and service providers for referrals
1	Close contact and availability of service providers
1	Offer of ICT support for less-skilled informal carers

Case Study 6

The Italian partner Anziani e Non Solo (ANS) decided to use as main scouting channels digital ones, since the purpose was for an online support group.

The main tool was a call for participants launched through social networks, as a e-card on *Facebook*.



However, other methods were used as well including:

- Direct invitation to participants that were known to the organizers as being carers of people with dementia not participating to any support group
- Snowballing: one participant inviting another
- Dissemination of the invitation to participate via the networks of the facilitators (mailing list, known NGOs working with people with dementia…)
- Distribution of digital leaflets through *WhatsApp* to direct contacts of ANS.

Figure 3- E-card to recruit participants

Tools
- Digital leaflet
- Facebook card
- Project website

Means
- Social networks
- Snowballing
- Direct invitation

Through this approach, we got in touch with 22 informal carers who expressed an interest to join the online groups.

3.4. Delivery of online support

"Participation to the group should not be perceived as an extra-task for the carer"

Web-based mutual aid groups for informal carers are very seldom implemented, despite being valued by experts and practitioners. Online mutual aid groups foster social inclusion through ICT by giving the possibility to participate to the group to people that, for various reasons, cannot access groups organized by local associations or structures.

The online support shall address two main aspects: emotional support and skills development. The general objectives of any kind of support group to informal carers shall cover, in full or partially, the **increase of their personal skills to deal with emotional aspects**[T1], the creation of a space for listening and sharing based on the principles of mutuality, respect and confidentiality, and the promotion of knowledge on how to manage their situation.

The Care4Dem model proposes an online support which can provide both ***synchronous and asynchronous support to informal carers***, ensuring that the information shared can be taken by participants at their own pace.

While asynchronous support relays on sharing documents and messages in an offline mode, **synchronous support runs lively putting the role of facilitator as a key element**[T2]. Despite this, ***the Care4Dem model envisages a light facilitation approach***. This means that facilitators should intervene to facilitate interaction among participants, making sure basic rules are respected, and ensuring that the group is a safe-place and participants are signed-posted if needed. Role of facilitators is also to take notes of what was discussed during the session, to serve as a thread for the following one.

[T1] Testimonial

"In this group, I saw a real need for communication and socialization of informal caregivers, as they mentioned quite often depressive-anxious states, stigma, and loneliness". (Facilitator, Romania)

[T2] Testimonial

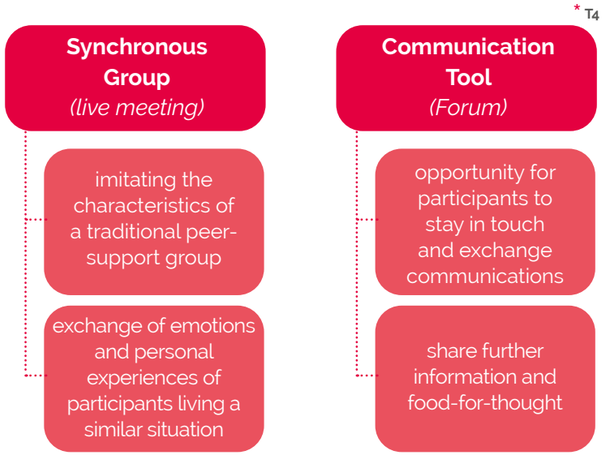
"During the path I didn't feel the burden of having contact with the participants through a PC and this struck me a lot because I believed that the fact of not speaking frontally would be perceived. Indeed, I think it probably wouldn't have been as easy to open emotionally without feeling the "protection" of the screen."
(Facilitator, Italy)

How to do this

1. Define the structure of the group
2. Familiarize with the web platform
3. Organise the information you will promote through asynchronous and synchronous
4. Create the link to your online group meetings using Skype[2]
5. Schedule your groups
6. Implement the synchronous sessions
7. Monitor the discussion on the forum (asynchronous)

Tools & Activities

The Care4Dem online support group is explicitly nontherapeutic. This means the treatment of psychological disorders is not the goal of the intervention and that the relationships occur primarily between peers, where **professionals only have a supportive role**[T3].



[2] This software was chosen considering it is free. If you have other software, you may use it instead.

[T3] Testimonial

"I was favourably impressed and today I'm convinced that [the use of ICT] does not affect the relationship. I saw the ease with which the participants, strangers, were able to tell each other even intimately and emotionally, and for example how it wasn't necessary introduce a rule for the speaking time, it was self-regulating even if at a distance." (Facilitator, Italy)

***Tip**

Collect the resources that are shared during the group discussions, compile them and share the document on the forum, as it works as a great tool to disseminate relevant information that is raised during sessions.

[T4] Testimonial

"The group connected very quickly and they manage the process by themselves. What I saw is that they really appreciate the group and they just want to talk."
(Facilitator, Portugal)

[T5] Testimonial

"Group rapport with icebreakers is key in the initial stages - perhaps even have the first session devoted to 'getting to know you".

(Participant of staff training, UK).

****Tip**

During the 1st session, bring into discussion the expectations of the caregivers from the group.

*****Tip**

During the experimentation, it has been noticed by facilitators that some participants connected later than the fixed time. This has generated the doubt whether to not greet the person who arrived so as not to "break" the atmosphere that had been created but risking making feel not considered the person or whether to greet the latecomer and stop the discussion. In this case it is better that the facilitators let the caregivers choose spontaneously what to do, reminding that are them that have to build the group relationship.

The access to the features of the online mutual aid groups happen to a simple web-platform, based on the open source software Moodle. ***The online platform is accessible from https://care4dem.eu/***[3]. The tutorials and online groups are available in five languages: English, Italian, Portuguese, Romanian and Spanish.

When (which day and at what time) the group should meet can be decided by the group or by the facilitators, considering the characteristics of the group or after conducting a poll among participants. As a service provider, you may group your participants based on their availability and preferences set at registration form.

The duration of each session varies according to the number of participants, but it is useful to keep a limited standard duration, as participating via teleconference is more tiresome than doing it in a face-to-face meeting. An average between 60 and 90 minutes is recommended.

When it comes to topics to be discussed[T5], participants have the decision-making. Concepts of democracy and equality should always be taken into account. The **facilitator shall promote the discussion and the decision-making of members****, in order to have an **autonomous and responsible group*****, reserving for him/herself taking relevant notes a ***reporting the session***.

In brief:

Web-based mutual aid groups model (check detailed output)

Tool#8 Meeting topics

Tool#9 Suggestions for Facilitation of Online Sessions

Tool#10 Session Report

[3] The web-platform remains available until 2022.

Critical Success Factors

- ICT literacy of participants
- Relevance of information shared within asynchronous space
- Adequate facilitator
- Right number of participants per group (not too small, neither too large)
- Similarity of profiles within the groups (in terms of age, relationship with the person they care for..)

Case Study 7

In Romania, the first online support group started with 11 participants who met every two weeks for about 90 minutes. The facilitators were an informal caregiver with experience and a psychologist. The co-facilitation process was very smooth since the facilitators established their roles and boundaries for each session, according to the topic, and took some time to debrief each session and organize the next ones. The participants expressed their interest to meet more often.

The 2nd group started with 9 participants and has been facilitated by an informal carer with experience and a social worker, who was also involved in the implementation of the project. This time, the sessions took place on a weekly basis. The group members decided to do so to create a routine and make sure they did not forget about the session. The Romanian partner EaSI decided to send a reminder, a text message, every week, the day before the sessions.

During the sessions, the caregivers shared their burden of providing care to a loved person and expressed their feelings (fear, sadness, anger, anxiety, grief, dejection, despair, but also nostalgia, relief, and satisfaction). They also discussed the caring process and how the CARE4DEM group brings them comfort.

The main topics discussed during the sessions were:

- Problems frequently encountered by informal carers (supervision, visits, moments of depression, or outrage of those under caring) and how each informal carer coped with the situation.
- The psychotherapeutic approach of patients (cognitive-behavioural therapy, art therapy, melotherapy, drama therapy).
- The past and present activity of the person suffering from dementia.
- How to deal with the elderly person's hospitalization in a care institution.
- What is the available support offered by the state institutions for people with dementia and for their carers.
- Types of services for people with dementia (e.g. therapy centers).
- The state of health and mental state of each caregiver.
- Ways to relax for each caregiver, especially discussions about holidays.
- Ways to socialize and detach, in addition to the daily tasks of informal care: work, online and offline socialization activities, recreational / sports activities, religious activities, volunteer activities.

3.5. Assessment and evaluation

"initiatives developing web-based mutual aid groups for carers share a series of common challenges, and the development of this promising tool would benefit from evaluation and cross-country analysis"

Adequate funding should be devoted to the development of initiatives supporting informal carers at local level, while creating synergies between interventions offered. The engagement and commitment of public authorities towards informal carers is a crucial step to reach a wider group of informal carers. This can only be achieved by providing reliable data on the effectiveness of the model and the outcomes raised in informal carers. Besides, **by showcasing the baseline condition of a group of informal carers and the positive effects of an intervention**[T1] (as the one of Care4Dem model) promotes awareness of the issues faced by informal careers in the context of the demographic change within public opinion and public authorities.

Structured and systematized evaluation measures always put a lot of pressure on providers, as they are time consuming. The financial limitations jeopardize the scale-up effect and restrain local initiatives from prospering in offering continuous support to informal carers and keep addressing their needs.

Regardless the type of funding you get, a process of evaluation shall be prepared and introduced, which can provide a minimum set of indicators on outcomes obtained by the intervention.

[T1] Testimonial

"During the meetings I noticed that the moment of sharing experiences among the participants also became an opportunity to reflect on the need to act on a social level, raising awareness among institutions on the issues of care to people with dementia and their caregivers. All of us caregivers, group's participants and facilitators included, have strengthened our conviction that our role deserves attention and must also be recognized on a social level." (Facilitator, Italy)

How to do this

1. Identify what outcomes you expect to reach through the intervention
2. Define your budget for evaluation (time, effort)
3. Check the Evaluation Protocol and compare it to your plans
4. Identify the items you can keep (or use the full version if you can)
5. Deliver the pre-evaluation form and compose the profile of your participants
6. Supervise facilitators and ask for ongoing evaluation
7. Deliver the post-evaluation
8. Deliver the follow-up evaluation
9. Report your achievements and constraints

***Tip**

In order to constantly analyse and evaluate the progress of the group participants' path, it would be useful for the facilitators at the end of each meeting to spend 10-15 minutes to discuss the progress of the session, so that it is possible to detect any difficulties or critical aspects of the group and offer better facilitation.

Tools & Activities

Evidence showed that the participation in mutual aid groups with the help of technology has effects on burden, depression, and self-efficacy of informal carers. You may stick to these outcomes or you may identify other which might adapt to your context.

The online support group can be evaluated regarding the profile of participants, the process, and the results achieved **(effects)***.

Profile	Process	Results
• sociodemo-graphic aspects • context of care	• number of groups • number of informal carers joining • ICT usability	• self-efficacy • care related quality of life • depression • experience of participation

5. Assessment and evaluation

The ***evaluation protocol*** provides you with a full questionnaire to measure the aspects of profile and results. Participants enrolled in the online support group can be assessed before the beginning of the group and on a follow-up moment in order to evaluate its effects. The follow-up can be defined according to the time you have available, but as a common standard you may deliver it every 3 months.

Before the beggining of the group → **Follow-up**

In brief:
Tool#11 Evaluation Protocol

Critical Success Factors[T2]

- Clarity of outcomes expected
- Feasibility of evaluation protocol
- Data analysis and report
- Frequent reminder to participant to fill in the questionnaires

Case Study 8 (Italy)

The evaluation questionnaires were created using the open-source programme Lime Survey (https://www.limesurvey.org/). Lime Survey ensures the possibility to easily translate questionnaires in different languages and also ensures the possibility to anonymise IPs of participants, making the responses totally anonymous.

When informal carers have been recruited for the piloting, Italian partner Anziani e Non Solo explained to them that the project was experimental and that they wanted to carefully evaluate it, in order to know its effects and also to fine-tune the model before a final release. Therefore, they were requested consent to be involved in such a research.

Links to access the pre, post and follow up evaluation questionnaires were sent to participants by email and frequent reminders were also sent, to encourage participation.

Despite this, is worth to say that Anziani e Non Solo didn't manage to collect 100% of questionnaires: over 12 participants to the evaluation process, they got 9 responses at the pre and post test and only 2 at the follow-up.

Nevertheless, the information collected during the evaluation were very useful and they recommend trying to implement such a process in a piloting phase, to ensure that there is evidence of the impact of the intervention and that opinions of participants are taken into account before the model is finalized.

[T2] Testimonial

"The most important change I noticed in the participants concerns a specific caregiver. During the first meeting it was possible to notice how her clothing was very covering, with her hair gathered, with a very enveloping scarf and with a slightly diffident attitude. After the first half hour of session I saw that she had taken off her scarf and I felt that she felt more comfortable after talking a lot about her reality, focusing in particular on how she had left the city in which she had grown up and her career for dedicate herself to the role of caregiver. In subsequent sessions she talked about how she was starting to put her career back into play by starting an online training course as a hotel manager, looking for future employment in his area of residence, a highly tourist area. But the most noteworthy thing was in the last meeting, just before Christmas, when, as soon as the session started, she greeted us very warmly with a new haircut, with an elegant sweater and with a hairband with two reindeers, just to welcome us with a strong Christmas spirit.

Certainly, her path was the one that struck me most and that made me understand that the Care4Dem project is working."

(Facilitator, Italy)



04

Available resources for Care4Dem online mutual aid groups

Available resources for Care4dem online mutual aid groups

	Further adaptations
1. Care4dem responsibilities of facilitators	Adapt to specific situations and profile defined
2. Care4dem roles of facilitators	
3. Care4dem rules of facilitators	Introduce specificities of own context and programme Add additional rules
4. Care4dem inclusion criteria	Add another criterion Adapt to own context
5. Poster for scouting caregivers	Introduce the specific details of your service/ initiative
6. Care4dem registration form	
7. Care4dem admission scripts	
8. Care4dem meeting topics	
9. Suggestions for facilitation of online sessions	
10. Care4dem session report	Run it online
11. Care4dem evaluation protocol	Make it shorter Select the specific dimensions you wish to support

1. CARE4DEM RESPONSIBILITIES OF FACILITATORS

What are facilitators expected to do?

Make the discussion easier, safe and adequate

- ☐ Help to maintain a safe (physically and emotionally), friendly, and warm environment that encourages mutual support and an opportunity to participate
- ☐ Help to facilitate balanced discussion
- ☐ Be an active listener
- ☐ Implement the ground rules and, if needed, mediate any conflicts that arise
- ☐ Maintain confidentiality
- ☐ [as a professional] Recognize when a member's concerns are beyond the group's ability to help and be willing to suggest alternative resources
- ☐ [as a professional] Recognize when clearly wrong or potentially dangerous information are conveyed in the group and suggest that the topic is discussed with an expert

Practical support to group management

- ☐ Remember to participants upcoming meetings, if necessary
- ☐ Begin and conclude meetings on time, if necessary
- ☐ Maintain group attendance records
- ☐ Maintain group monitoring records
- ☐ Provide basic ICT support to help accessing the online tools

2. CARE4DEM ROLES OF FACILITATORS

Role	Asset/ added value	Specific tasks
Informal carer	Caring experience Allaying participants' fears Communicating information in relatable terms	Moderator of the discussion Reference person of the group
Professional	Fostering use of mutual aid groups among informal carers Ensuring structure and systematization	Supportive roles (minute taker, scribe, timekeeper, vibes watcher, gatekeeper) In the first sessions, professional might have a more active role in the facilitation, assuring that the group follows the structure of the model

Common and generic aspects: Trust and Collaboration

3. CARE4DEM RULES FOR FACILITATORS

Welcome! You are now a Facilitator of an Online Support Group for Informal Carers at [name of provider]. You are entering in a process of co-facilitating an online support group voluntarily. Please bear in mind the following rules for facilitators to ensure a smooth co-facilitation process.

1. Co-facilitators should never publicly criticize or argue with each other during the meeting: this behavior will only serve to damage the relationship and lose the trust of the group.
2. Co-facilitating with strangers it's very difficult! Facilitators should meet (e.g. on-line) each-other in advance to get to know more about their experience and facilitation style. Discussing roles and mutual expectations can avoid unpleasant surprises for them and the group.
3. From the 3rd meeting onwards, the professional facilitator shall participate to the group only in audio, without keeping his/her webcam on. This would support the idea of ownership of the group by the informal carers, while allowing him/her to still follow the discussion and intervene in case it is needed.
4. It is important to always communicate with the co-facilitator – before, after and during group.
   a. BEFORE: discuss time limits, working with silence, signals
   b. DURING: communicate with body language, signals
   c. AFTER: discuss what went well, what issues may have come up
5. Debriefing is of special importance as allows the opportunity to check in with the partner immediately after group and while things are still fresh in mind. It is easy to forget what happened in the group by the next session, so it is good to schedule this time immediately after each session. A debrief should only last approximately 10-15 minutes unless a significant issue came up you need to follow up on. There are three major pieces to cover in a debrief:
   a. What went well?
   b. What didn't go well?
   c. What new skills, knowledge, or systems do we need to develop moving forward to be a more effective team?
6. It is important to be open to improvement or adaptation as a facilitator as well as in sharing ideas and feedback to the co-facilitator.
7. Every session, facilitators shall compile the information from debriefing and record it in the "Session Report" (tool#10).

4. CARE4DEM INCLUSION CRITERIA

For the informal carer:

- Being 18+
- Being an informal carer of a person with dementia
- Have access to ICT devices (e.g. computer, smart phone) and have ICT skills (see below)
- Accept and consent to participate in the group
- For the care recipient:
- Condition of dementia, or symptoms of cognitive decline (e.g. difficulties in memory, executive function, attention, temporal or space disorientation);
- Need care/help in any of the activities of daily living (e.g. dressing, bathing, shopping, paying bills) and/or supervision

ICT skills:

As minimum level of skills, participants should be able to:

- Turn on their devices
- Connect headphones, webcams, and microphones to it (if not incorporated) and regulate volume settings
- Connect their devices to the internet
- Have an email and be able to use it to respond to messages and download documents.

5. POSTER FOR SCOUTING CAREGIVERS



6. CARE4DEM REGISTRATION FORM

- ☐ Name (First and Surname)
- ☐ E-mail
- ☐ Phone number
- ☐ Relationship with the care recipient: spouse | offspring | brother/sister | friend | other
- ☐ Availability for the online meetings:
  - morning | afternoon | evening
  - Monday | Tuesday | Wednesday | Thursday | Friday

After submission, the following message shall appear:

Thank you for your registration. You will soon be contacted through the provided email.

7. CARE4DEM ADMISSION SCRIPTS

First Email

After registration, a standard email shall be sent to each participant with the following information: a thank you note, some information about the corresponding service provider and a note that team will contact by phone soon.

A possible outline for this email is:

> *Thank you for your interest and registration in the online support group of [name of service provider]. This programme is managed by [name of coordinator].*
>
> *To confirm your availability to participate in the online support group, one of the team members will contact you with more details as soon as possible.*

Phone-Call

After establishing contact via email, the service provider shall contact the possible participants via phone. This phone-call shall cover:

1. Presentation of the team member: *Hello, my name is […] and I am contacting you on behalf of [name of service provider]. We received your registration on the online mutual aid groups for informal carers and I would like to confirm some details with you.*
2. Confirmation of the following:

- Interest to participate (*Are you still interested in participating in this online group?*)
- Understanding of the support group's objectives (*Do you understand what this support group is? Do you have any question regarding how it will work?*)
- Inclusion criteria

After all these topics are covered, ask the participant if he/she agrees and still wants to participate. If the answer is yes, inform the participant that the consent form will be sent (the inform consent can be sent by post, with an extra envelop with return stamp or by email, according to the preferences of the participant).

Inform the participant that after establishing the different groups, he/she will be contacted with more details.

8. CARE4DEM MEETING TOPICS

Normally, a support group is based on inputs from participants and does not have a pre-defined list of topics to be discussed. Due to the novelty of this type of intervention among informal carers, as a common standard, here are some guidelines for the first meeting (introduction).

Meeting 1 – Intro

During the initial meeting, it is important that the following topics are discussed / introduced:

- Presentation of facilitators
- The concept of peer-support
- Ice-breaking: ask each participant to tell his/her name
- Ground rules of the group (respect – non-judgmental attitude and confidentiality, inclusion)
- Presentation of participants: ask each participant to tell for whom he/she cares for – for how long he/she has been doing it
- Review of the web-platform and its features

A possible introductory script for this initial session can be the following:

Welcome to this 1st meeting of our online peer-support group. How are you today? Can everybody hear me and seeing me well? *[if necessary, take a minute to solve some technical issues]*.

My name is … and together with … we will be the facilitators of this group, and I am also an informal carer / a former carer. My role in this group is to help you initiating the discussion and making the communication flow a bit easier for everyone, while *[name of professional]* is mostly here to assist me, if needed.

As you know, this is a peer support group. It means that we are all are informal carers of a person with dementia and we want to share our experiences, feelings, difficulties and thoughts about how it is like to be an informal carer. In fact, sometimes we might believe we are the only ones experiencing this but by discussing together we will probably realize that this is not the case. Also, it is possible that some of us have already experienced something which is new for others and it can be useful to hear other experiences and possibly learn from them.

Anyone have any question so far? So, I suggest that we start by introducing ourselves by saying your names.

Thank you very much. Now that we know everyone's name, I would like to talk with you about the functioning of the sessions.

Our conversations will be really informal, and you are free to discuss whatever you deem appropriate, however there are some very basic rules that it is important we all agree upon. *[Present core rules and ask participants if they agree on them and if there is anything else, they would like to add].*

Now, it would be nice if we can start getting to know each other a little bit more…

Thank you! It was nice to start getting to know each other a little bit more *[here you can point out if in the presentations there were similarities or anything nice that came out of this first session]*.

The sessions of this online support group are free, you can talk about any issue or concern related to caregiving. If you all agree, in the beginning of each session, if someone has something to share and discuss with the group, this person can start the session with that, and we follow from there. It is not expected I or my colleague lead the group, neither to train you in the caregiving role. We are here mainly to facilitate communication. This time and space are yours, for you to share your experiences, joys, and challenges, and to rely on your peers understanding, non-judgment and support.

Before we conclude our session today, I would like to remember you that in our web-platform there is a forum that you can use to remain in touch between this session and the next one. Should there be anything that you would like to discuss or share with the rest of group, please feel free to post it in the forum.

So, thank you for your time today – I hope you enjoyed. Don't forget that our next meeting will be on… at … "

9. SUGGESTIONS FOR FACILITATION OF ONLINE SESSIONS

A list of suggestions to facilitate a session, from the beginning to the end, and to face some common but challenging issues that might raise:

Getting the discussion started – Begin your session by welcoming participants and briefly recalling the group ground rules. If the group doesn't begin talking spontaneously, to kick off the discussion, you can ask questions such as "is there anything happened last week / in the previous 2 weeks that any of you would like to share"? Or you could go around in a circle and asking each member a "HIGH/LOW" of their week. A HIGH can be something positive in their life. A LOW can be something not so great in their life. Highs and Lows don't necessarily have to be associated with caring.

Reinforcing – Remember: to keep the discussion flowing, people's comments should be reinforced. A "Thank you," "Good idea!" or simply a smile and nod of the head can be reinforcing. Silence is not reinforcing. Criticism and judgmental comments are negative reinforces.

Managing time-monopolizers – When one of the participants monopolize the discussion, the facilitator should try to assure that the other attendees have the opportunity to participate as well. For example: "It sounds like you experienced a lot of difficulty this past month taking care of your mother and it put a lot of stress on you while trying to get through your new job. Is this an experience other can relate to or have worked through in the past?"

Encouraging nonparticipants – The facilitator should remain aware of who is contributing and who is not. People who are not participating can be called on by name and asked for their ideas, but it's only safe to do this once. Some people find that speaking in public is so stressful they will avoid it at all costs. Insisting that they participate or calling on them more than once only increases their discomfort.

Handling extreme emotion – Sometimes a group member will break down crying in the middle of a comment. If there is no answer from the group, an empathetic comment such as, "I can see it really hurts you to talk about this," is appropriate. You might also ask if that individual wishes to continue or if you should go on to someone else and come back to that person later. The appropriate impression to impart is that it's acceptable to have emotions, and it's OK to cry. In extreme cases, you might call a short recess, during which you or another member can comfort the person privately.

Managing the silence - silence can be really uncomfortable, but it is important as it allows peers a moment to think – especially people who are not as verbal or quick to respond, helps facilitator see what topics make group uncomfortable and allows the pace to shift or slow down. A possible reaction could be to say something like: "I noticed the group fell silent after that last statement. Anyone wants to comment, or should we change the subject?"

Ending the discussion – When it's time to end the discussion, and if the group doesn't assume it spontaneously, try to conduct participants to an end-point in their discussion and thank everyone for their participation. Remember that it is important to conclude the session on time for respect of the time of all participants.

10. CARE4DEM SESSION REPORT

Group name_____ **Date** __/__/____

Starting hour _____ **End hour** _____ **SESSION Nº** _____

Facilitator (1) _____ **Facilitator (2)** _____

SUMMARY (describe the major issues discussed in the session):

PARTICIPANT EVALUATION

For each participant evaluate with 1 to 5 the next areas (use the score 2 and 4 for middle evaluation)

	NAME*	Present? YES/ NO	Interest*	Communication*	Initiative*	Satisfaction*	Mood*
1.							
2.							
3.							
4.							
5.							
6.							
7.							

**** Notes:***

Name: in the online version it should appear the code (instead of the name of the participant)

Interest – level of interest about the discussion/ activity, requiring more or less reinforcement 1 – without interest 3 – some interest 5 – great interest	**Satisfaction** – level of enthusiasm and well-being during the session 1 – doesn't reveal satisfaction 3 – reveal some satisfaction 5 – reveal lot of satisfaction
Communication – level of interaction with the other participants 1 – little or none communication 3 – some communication 5 – good communication	**Mood** – state of mind, which reveals the disposition level and the emotional and psychological well being 1 – seems anxious/ depressive 3 – some signals of good mood 5 – seems happy and relaxed
Initiative – level of proactivity in the relationship with the other participants (e.g. give suggestions, ask for help, help the others) 1 – without initiative 3 - some initiative 5 – lots of initiative	

SESSION EVALUATION

What is your global opinion about the quality and development of the session?

1. Poor		2. Unsatisfactory		3. Satisfactory		4. Very Satisfactory		5. Outstanding	

COMMENTS *(please describe if there are any difficulties related with the group, or with the use of ICT; anything out of the ordinary should be reported here):*

SKILLS APPLICATION *(e.g give some examples of the skills you applied during the session; do you think the facilitator training you received should train other skills? If yes, please describe them):*

11. EVALUATION PROTOCOL

As part of the [name of the programme], we would like to have your collaboration to answer the following questionnaire. In order to help us, you just have to answer carefully the questions that are asked in this questionnaire, which will not have other treatment than the statistical one in aggregate data.

We would like to thank you in advance for your participation.

GENERAL INFORMATION (ADAPTED FROM THE RESOURCES UTILIZATION IN DEMENTIA - RUD©) [4]

1. Moment of evaluation: Participant's code:_____

a) Pre-test ☐

b) Follow-up ☐

2. Date:___/___/_____

A1. CAREGIVER

A1.1. Description of Primary Caregiver

3. Age _____years

4. Sex:

a) Male ☐

b) Female ☐

c) Other ☐

5. Relationship with the person you care for:

a) Spouse ☐

b) Sibling ☐

c) Child ☐

d) Friend ☐

e) Other: _____ ☐

(professionals will not be considered)

6. Number of children currently living with you: _____ child(ren)

7. Do you live with the care receiver?

a) Yes ☐

b) No ☐

8. How many other informal caregivers are involved in the care (please do not consider professional help)?

a) 0 ☐

b) 1 ☐

c) 2 ☐

d) 3 ☐

e) 4 or more ☐

9. Among all informal caregivers what is your level of contribution regarding the provision of care?

a) 1 – 20% ☐

b) 21 – 40% ☐

c) 41 – 60% ☐

d) 61 – 80% ☐

e) 81 – 100% ☐

10. Do you have any professional help?

a) Yes ☐

b) No ☐

If your answer is yes, please specify what kind of professional help: _____

_____

A1.2 Caregiver Time

11. On a typical care day during the last 30 days, how much time per day and night did you spend asleep? _____ hours and _____ minutes per day and night.

12. For the past 30 days have you performed tasks such as helping the care receiver...:

	Yes	No
a) ...go to the toilet?		
b)...feed himself/herself?		
c)...get dressed?		
d)...walk?		
e)...take a shower?		
f)...go shopping?		
g)...prepare meals?		
h)...take care of the house?		
i)...treating clothes?		
j)...transportation?		
k)...taking medication?		
l)...managing financial matters?		
m)...supervising the care recipient?		

13. On a typical care day during the last 30 days, how much time per day did you spend in performing the previous tasks? _____ hours and _____ minutes per day and night.

(Note that total time spent sleeping and performing task must not exceed 24h)

GENERAL SELF-EFFICACY SCALE (GSE)[5]

	Not at all true	Hardly true	Moderately true	Exactly true
1. I can always manage to solve difficult problems if I try hard enough.				
2. If someone opposes me, I can find the means and ways to get what I want.				
3. It is easy for me to stick to my aims and accomplish my goals.				
4. I am confident that I could deal efficiently with unexpected events.				
5. Thanks to my resourcefulness, I know how to handle unforeseen situations.				
6. I can solve most problems if I invest the necessary effort.				
7. I can remain calm when facing difficulties because I can rely on my coping abilities.				
8. When I am confronted with a problem, I can usually find several solutions.				
9. If I am in trouble, I can usually think of a solution.				
10. I can usually handle whatever comes my way.				

CARE RELATED QUALITY OF LIFE (CARERQOL)[6]

CarerQol-7D

We would like to form an impression of your caregiving situation. Please tick a box to indicate which description best fits your caregiving situation at the moment.

Please tick only one box per description: 'no', 'some' or 'a lot of '.

	No	some	a lot	
a. I have				fulfilment from carrying out my care tasks.
b. I have				relational problems with the care receiver *(e.g., he/she is very demanding or he/she behaves differently; we have communication problems).*
c. I have				problems with my own mental health *(e.g., stress, fear, gloominess, depression, concern about the future).*
d. I have				problems combining my care tasks with my daily activities *(e.g., household activities, work, study, family and leisure activities).*
e. I have				financial problems because of my care tasks.
f. I have				support with carrying out my care tasks, when I need it *(e.g., from family, friends, neighbors, acquaintances).*
g. I have				problems with my own physical health *(e.g., more often sick, tiredness, physical stress).*

CarerQol – VAS

How happy do you feel at the moment?

Please place a mark on the scale below that indicates how happy you feel at the moment.



Perseverance Time

If the informal care situation stays as it is now, how long will you be able to cope with the care?

(i) less than one week;

(ii) more than one week, but less than one month;

(iii) more than one month, but less than six months;

(iv) more than six months, but less than one year;

(v) more than one year, but less than two years;

(vi) more than two years.

BECK'S DEPRESSION INVENTORY

This questionnaire consists of 21 groups of statements. Please read each group of statements carefully and then pick out the one statement in each group that best describes the way you have been feeling during the past two weeks, including today. Circle the number beside the statement you picked. If several statements in the group seem to apply equally well, circle the highest number of that group. Be sure that you do not choose more than one statement for any group, including Item 16 (Changes in Sleeping Pattern) or Item 18 (Changes in Appetite).

1. Sadness

0. I do not feel sad.
1. I feel sad much of the time.
2. I am sad all the time.
3. I am so sad and unhappy that I can't stand it.

2. Pessimism

0. I am not discouraged about my future.
1. I feel more discouraged about my future than I used to be.
2. I do not expect things to work for me.
3. I feel my future is hopeless and will only get worse.

3. Past Failure

0. I do not feel like a failure.
1. I have failed more than I should have.
2. As I look back, I see a lot of failures.
3. I feel I am a total failure as a person.

4. Loss of Pleasure

0. I get as much pleasure as I ever did from the things I enjoy.
1. I don't enjoy things as much as I used to.
2. I get very little pleasure from the things I used to enjoy.
3. I can't get any pleasure from the things I used to enjoy.

5. Guilty Feelings

0. I don't feel particularly guilty.
1. I feel guilty over many things I have done or should have done.
2. I feel quite guilty most of the time.
3. I feel guilty all of the time.

6. Punishment Feelings

0. I don't feel I am being punished.
1. I feel I may be punished.
2. I expect to be punished.
3. I feel I am being punished.

7. Self-Dislike

0. I feel the same about myself as ever.
1. I have lost confidence in myself.
2. I am disappointed in myself.
3. I dislike myself.

8. Self-Criticalness

0. I don't criticize or blame myself more than usual.
1. I am more critical of myself than I used to be.
2. I criticize myself for all of my faults.
3. I blame myself for everything bad that happens.

9. Suicidal Thoughts or Wishes

0. I don't have any thoughts of killing myself.
1. I have thoughts of killing myself, but I would not carry them out.
2. I would like to kill myself.
3. I would kill myself if I had the chance.

10. Crying

0. I don't cry any more than I used to.
1. I cry more than I used to.
2. I cry over every little thing.
3. I feel like crying, but I can't.

11. Agitation

0. I am no more restless or wound up than usual.
1. I feel more restless or wound up than usual.
2. I am so restless or agitated that it's hard to stay still.
3. I am so restless or agitated that I have to keep moving or doing something.

12. Loss of Interest

0. I have not lost interest in other people or activities.
1. I am less interested in other people or things than before.
2. I have lost most of my interest in other people or things.
3. It's hard to get interested in anything.

13. Indecisiveness

0. I make decisions about as well as ever.
1. I find it more difficult to make decisions than usual.
2. I have much greater difficulty in making decisions than I used to.
3. I have trouble making any decisions.

14. Worthlessness

0. I do not feel I am worthless.
1. I don't consider myself as worthwhile and useful as I used to.
2. I feel more worthless as compared to other people.
3. I feel utterly worthless.

15. Loss of Energy

0. I have as much energy as ever.
1. I have less energy than I used to have.
2. I don't have enough energy to do very much.
3. I don't have enough energy to do anything.

16. Changes in Sleeping Pattern

0. I have not experienced any change in my sleeping pattern.

1a. I sleep somewhat more than usual.

1b. I sleep somewhat less than usual.

2a. I sleep a lot more than usual.

2b. I sleep a lot less than usual.

3a. I sleep most of the day.

3b. I wake 1-2 hours early and can't get back to sleep.

17. Irritability

0. I am no more irritable than usual.

1. I am more irritable than usual.

2. I am much more irritable than usual.

3. I am irritable all the time.

18. Changes in Appetite

0. I have not experienced any change in my appetite.

1a. My appetite is somewhat less than usual.

1b. My appetite is somewhat greater than usual.

2a. My appetite is much less than before.

2b. My appetite is much greater than usual.

3a. I have no appetite at all.

3b. I crave food all the time.

19. Concentration Difficulty

0. I can concentrate as well as ever.

1. I can't concentrate as well as usual.

2. It's hard to keep my mind on anything for very long.

3. I find I can't concentrate on anything.

20. Tiredness or Fatigue

0. I am no more tired or fatigue than usual.

1. I get more tired or fatigue more easily than usual.

2. I am too tired or fatigue to do a lot of the things I used to do.

3. I am too tired or fatigue to do most of the things I used to do.

21. Loss of Interest in Sex

0. I have not noticed any recent change in my interest in sex.

1. I am less interested in sex than I used to be.

2. I am much less interested in sex now.

3. I have lost interest in sex completely.

ITEMS TO INCLUDE IN THE FOLLOW-UP EVALUATION

EXPERIENCE OF PARTICIPATION IN THE SUPPORT GROUP[7]

Support Group Experience

In relation to your participation in the Support Group, mark with an X the option that best suits your situation.

	STRONGLY DISAGREE	DISAGREE	AGREE	STRONGLY AGREE
1. Contributed to increase my ability to take care of my relative.				
2. Has helped me to recognize that it is important to take care of myself.				
3. Has helped me to improve my quality of life.				
4. Has helped me to improve my family member's quality of life.				
5. Demanded too much from me.				
6. Helped me to understand the relationship between stress, care and my health and wellbeing.				
7. Provided me with useful information.				
8. It helped me to better understand my family member's illness.				
9. Helped me to better deal with my emotions.				
10. Helped me how to take better care of myself.				
11. Helped me feel more secure and confident in my role as caregiver.				
12. Allowed to meet new people and make some friendships.				
13. It made me accept my situation better.				
14. It gave me knowledge that allowed me to improve the relationship I have with my relative.				
15. It made me feel useful for sharing my experience with other caregivers.				
16. It made me realize that there are other people in the same situation as me and that what I feel is normal.				
17. It made me feel happy for being able to help the other peer-support group elements to solve their problems				
18. Caregivers, by speaking about their experiences, helped me to solve/overcome my problems/ difficulties.				

Very unsatisfied	Unsatisfied	Not satisfied, nor unsatisfied	Satisfied	Very Satisfied

Briefly describe how important it was for you to participate in the sessions of the peer support group and what you considered more and less positive:

Please add any comments you find relevant:

Did you continued attending the support group or had any kind of social/ psychological support?

a) I continued attending the CARE4DEM MAG ☐

b) I had social/psychological support ☐

Specify: _____

c) No, I haven't had any kind of support ☐

Glossary

Blended-learning is an approach to education that combines online educational materials and opportunities for interaction online with traditional place-based classroom methods.

Competence Profile: A list of the competencies needed to do a job well. A competency profile (sometimes referred to as skills profile) is often created and used in organizations to evaluate candidates for a specific job but also to establish a developmental plan for employees based on the needs required for a position.

Dementia is an overall term for diseases and conditions characterized by a decline in memory, language, problem-solving and other thinking skills that affect a person's ability to perform everyday activities. Memory loss is an example. Alzheimer's is the most common cause of dementia.

E-literacy relates to the skill set required to make efficient use of all of the materials, tools, and resources that are available online.

Facilitation: The definition of facilitate is "to make easy" or "ease a process." What a facilitator does is plan, guide and manage a group event to ensure that the group's objectives are met effectively, with a supporting environment, with good participation and full buy-in from everyone who is involved

Health literacy is the ability to obtain, read, understand, and use healthcare information in order to make appropriate health decisions and follow instructions for treatment.

Informal carers are persons of all ages who provide care (usually unpaid) to someone with a chronic illness, disability or other long-lasting health or care need, outside a professional or formal employment framework.

Mutual Aid Group (MAGs) involve meeting with other people who share the same or similar circumstances or conditions to discuss and to share ways of coping and can be found in many areas such as physical disability, mental health, physical health conditions, groups for carers and addiction. Members usually meet at face-to-face meetings, but as use of the Internet increases, some groups hold 'virtual' meetings online. Sharing experiences enables them to give each other a unique quality of mutual support and to

pool practical information and ways of coping. Groups are run by and for their members, this definition differentiates mutual aid groups from individual self-help and from a support group that is led by a professional.

Peer support interventions build on the capacity of individuals who have experienced a challenging situation to support adequately others dealing with a similar situation. By listening empathetically, sharing their experiences and offering suggestions based on their own experience, these people are particularly able to help others in a comparable situation.

Additional resources

This section presents complimentary information of resources for caregivers, especially in online environments, not necessarily foreseen in the Care4Dem project, but connected to partners' activities.

Apps4carers

A representative from INRCA (National Institute of Health and Sciences on Ageing, Italy) participated in the Care4Dem training session in Amadora, PT (3-6 June 2019), and on this occasion some of their activities in the field of carers were presented. In particular, the Apps4carers project (Erasmus+, 2016-2018) was described.

Main objective of the A4C project was the development of a new mobile app dedicated to carers, a sort of «repository » of the apps, which include applications and websites selected among those currently available on the market to support family carers. This « repository » also include specific teaching materials for each of the selected applications aimed to facilitate their use, and is organized according to categories and filters to allow users to select the most appropriate resources to their needs. In addition, training sessions based on experiential learning were organised in each of the participant Countries (Sweden, Italy, Greece, Portugal and Cyprus) to provide carers with basic digital skills enabling them to use at best the proposed solutions. For further information visit: **http://www.appsforcarers.eu/.**

Café Memória from Alzheimer Association in Portugal

Due to COVID-19 restrictive measures, there can be found some online groups supporting informal caregivers. Alzheimer Association in Portugal runs the so-called Café-Memória (Memory Café) using zoom© platform, every week (**https://www.facebook.com/cafememoriapt/**). This group is open to everyone and the link to join the meetings is available in the Facebook© page. Every time, there is a different thematic topic and invited guest.

Online Dementia Skills Sessions

These are online sessions for carers to join with specialized dementia trainers and get to know more information and knowledge about the disease. The sessions are run for free. For further information visit: **https://dementiaadventure.co.uk/what-we-do/training-and-consultancy/free-events/**

tide – together in dementia everyday, an organisation for dementia carers in United Kingdom

An organization and network of and for carers and former carers, providing services in increasing skills, empowering and motivating carers, informing and helping carers of people with dementia. For further information visit: **https://www.tide.uk.net/resources/activities-for-carers-people-with-dementia/**

References

Amputee Coalition (2015). Support group manual. Available from: https://www.amputee-coalition.org/wp-content/uploads/2015/01/lsp_support-group-manual_090115-065319.pdf

Azevedo, M. J.; Boccaletti, L.; Tavares de Sousa, R. (2019). Web-based mutual aid groups model, in Care4Dem partnership. Available from: https://eurocarers.org/care4dem/innovative-model/

Banach, M., & Couse, L. J. (2012). Interdisciplinary co-facilitation of support groups for parents of children with autism: An opportunity for professional preparation. Social Work With Groups, 35(4), 313-329.

Beck, A. T., Steer, R. A. & Brown, G. K. (1996). Manual for Beck Depression Inventory II-Second Edition. San Antonio. TX: Psychological corporation.

Brouwer, W. B.; van Exel, N. J.; van Gorp, B. & Redekop, W. K. (2006). The CarerQol instrument: a new instrument to measure care-related quality of life of informal caregivers for use in economic evaluations. Qual Life Research, 16(6), 1005-1021. doi:10.1007/s1136-005-5994-6

Champeix, C. (2019). The CARE4DEM Facilitator's Competence Profile - Supporting professionals and volunteers to facilitate online Mutual Aid Groups for informal carers of people with Dementia. Available from: https://eurocarers.org/care4dem/for-facilitators/

Gomes, A.L., Gonçalves, P., Portugal, J. (2020). Care4Dem Training Handbook. Available from: https://eurocarers.org/care4dem/for-facilitators/

McKechnie, V., Barker, C., & Stott, J. (2014). Effectiveness of computer-mediated interventions for informal carers of people with dementia—a systematic review. Int Psychogeriatrics, 26(10), 1619-37.

Moreno, M. (coord.) (2018). Web-based mutual aid groups for informal carers of people with dementia: an evidence review. Executive Summary of the baseline study prepared in the framework of the Erasmus+ project CARE4DEM. Available from : https://eurocarers.org/care4dem/innovative-model/

Muñiz, R., Olazarán, J., Poveda, S., Lago, P. & Peña-Casanova, J. (2011). NPT-ES: A measure of the experience of people with dementia during non-pharmacological interventions. Non-Pharmacological Therapies in Dementia, 1 (3), 1-11.

National Alliance on Mental Illness (s.d). Peer support groups facilitation guide.

Papa R, Efthymiou A, Lamura G, Piccinini F, Onorati G, Papastavrou E, Tsitsi T, Casu G, Boccaletti L, Manattini A, Seneca R, Vaz de Carvalho C, Durão R, Barbabella F, Andréasson F, Magnusson L, Hanson E. Review and selection of online resources for carers of frail adults or older people in five European countries: a mixed-methods study. JMIR Mhealth Uhealth (in press) doi: 10.2196/14618

Projeto CuiDem – Cuidados para a Demência (DGS-SM-D 17-2014-4) (2015-2017). Protocolo de Avaliação. Porto: CAS050+, Associação.

Roose, R. J. & Cockerham-Colas, L. & Soloway, I. & Batchelder, A. & Litwin, A. H. (2014). Reducing Barriers to Hepatitis C Treatment among Drug Users: An Integrated Hepatitis C Peer Education and Support Program. Journal of Health Care for the Poor and Underserved 25(2), 652-662. Johns Hopkins University Press.

Schwarzer, R. & Jerusalem, M. (1995). Generalized Self-Efficacy scale. In J. Weinman, S. Wright, & M. Johnston, Mesures in health psychology: A user's portfolio. Causal and control beliefs. Windsor: NFER-NELSON.

Sheikh, J. I. & Yesavage, J. A. (1986). Geriatric Depression Scale (GDS): Recent evidence and development of a shorter version. Clinical Gerontology: A Guide to Assessment and Intervention, 165-173, NY: The Haworth Press.

Sweeney P. (s.d). Peer Support Group Facilitation Skills. New England MIRECC Peer Education Center.

The Alzheimer Society of PEI (s.d). Support Group Facilitation Training Manual.

Tracy, K., & Wallace, S. P. (2016). Benefits of peer support groups in the treatment of addiction. Substance abuse and rehabilitation, 7, 143-154.

Wimo A., Wetterholm A.L., Mastey V. & Winblad B. (1998). Evaluation of the resource utilization and caregiver time in Anti-dementia drug trials - a quantitative battery. In A.

Wimo, G. Karlsson, B. Jönsson & B. Winblad (eds), The Health Economics of dementia. London: Wiley´s.

Queluz, F.; Kervin, E.; Wozney, L.; et al (2019). Understanding the needs of caregivers of persons with dementia: a scoping review. International Psychogeriatrics (2020), 32(1): 35–52. Available from: https://www.cambridge.org/core/journals/international-psychogeriatrics/article/understanding-the-needs-of-caregivers-of-persons-with-dementia-a-scoping-review/11EEEDF142ADCD218AE7A537B52A1C78

[4] Adapted from: Wimo, A., Wetterholm, A.L., Mastey, V., Winblad, B. (1998). Evaluation of the resource utilization and caregiver time in Anti-dementia drug trials-a quantitative battery.In A. Wimo, G. Karlsson, B. Jönsson and B. Winblad (eds) .The Health Economics of dementia. London: Wiley's

[5] Original version: Schwarzer, R. & Jerusalem, M. (1995). Generalized Self-Efficacy scale. In J. Weinman, S. Wright, & M. Johnston, Mesures in health psychology: A user's portfolio. Causal and control beliefs. Windsor: NFER-NELSON

[6] Brouwer, W.B.F., van Exel, N. J.A., van Gorp, B. & Redekop, W.K. (2006). The CarerQol instrument: A new instrument to measure care-related quality of life of informal caregivers for use in economic evaluations. Qual of Life Res, 15(6), 1005-1021. doi:10.1007/s1136-005-5994-6

[7] Adapted from: Projeto CuiDem – Cuidados para a Demência (DGS-SM-D 17-2014-4) (2015-2017). Protocolo de Avaliação. Porto: CAS050+, Associação

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