



RESIL4CARE

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RESIL4CARE PR2 Development of RESIL4CARE training course manual and online materials for better resilience of informal carers

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1. INTRODUCTION

Family and other informal carers are people that provide unpaid care to someone with a chronic illness, disability or other long lasting health issues on a weekly or even daily basis. Informal carers are usually relatives (partners, children, daughters in law etc.), sometimes friends, neighbours, or volunteer professional workers (district nurses, physiotherapist etc.).

International research shows, that many people are willing to care for their loved ones. Main reasons for caring are ethical (responsibility towards family), emotional (belonging to a family, love for family), and also economical (formal care is difficult to access and expensive). In Europe, informal caregiving contributes to more than three quarters of all long-term care provided, around 80%, (Petrini et al., 2019) and according to Eurocarers (2017) statistics, the number of informal carers is more than 100 million.

Even though informal carers put great effort, love and determination into caring, caring for a person that needs a long-term care is not easy. Family carers can find themselves providing care overnight and more often than not they are not equipped with knowledge about the disease and nursing, they lack communication skills with person in need of help and all that can lead to conflicts and stressful situations. At the same time their work is often taken for granted. Furthermore, family carers often do not know where to search for help and what kind of support they should be looking for and sometimes the support itself is very inadequate and fragmental. Sometimes the challenge is that informal carers themselves are also elderly and/or ill and also need help. On top of that, middle aged carers often provide care both for children and for older relatives (so called "sandwich" carers) and beside that also have a job responsibility. Many times, they are forced to quit their job. All these factors are emotionally draining and contribute to the burn-out of family carers.

In order to help family carers, public, professional and systematic legislative support is needed. Carers need effective support of the health and social care system and other support services. Family carers also need direct support: knowledge and emotional support. They also need peer support, in order to feel that they are not alone in their situations. Family carer trainings that include in-group social learning proved very successful in this regard, where, in addition to theoretical and practical knowledge, people learn from their peers in similar situations. Knowing that you are not the only person in the world who also challenges while providing care is invaluable for family carers. For this reason, a number of family carers' groups have been formed, where the main purpose (besides education) is to share the experiences of family carers with each other.

Resil4Care is an European, Erasmus+ project (2022-2024) connecting people and organizations working with and for carers from Greece, France, Italy, Slovenia and Spain. Using modern technology and social media, RESIL4CARE project aimed at improving the resilience of informal carers. Trough joining the informal carers' social media community, we hoped to help informal carers feel less alone in their task and by providing practical information and psychological support on the platform we aimed at improving their quality of life.

The Resil4Care project has further reflected on new forms of support activities for family carers. We started from the assumption that lack of time together with geographical and sometimes personal circumstances sometimes make it difficult for informal carers to participate in face-to-face support groups. Besides that, we wanted to widen the scope of possibilities, enabling family carers to use one more channel of support. Since family carers belong to different age groups and come from very diverse cultural and educational backgrounds, we chose to work with social platforms that are more and more used also among different carers populations. Since in our respective countries Facebook was most widely used social platform for middle aged and older population (among which we can find majority of family carers) we decided on it, counting on it to have the potential to provide impactful and cost-effective online support to informal carers.

The purpose of the PR2 Development of RESIL4CARE training course manual and online materials for better resilience of informal carers was to deliver a training course manual on how to set up and run social media support groups and to provide online materials for informal carers to be used on social media platforms.

2. MODEL DESCRIPTION

1.1. STRUCTURE OF THE MODEL

The Resil4Care model is built on two interconnected levels that are structured on the realization that running of a social media platform requires dedicated team (engine) which has time and knowledge to create appropriate environment that can support family carers. During the project we named this dedicated team **a core group** and social media platform with its' members was called **an online (social media) support group**.

As described in the introduction, in the Resil4Care model, we chose Facebook as the social network of choice because we judged within the Resil4Care consortium that family caregivers are most likely to use Facebook. In this regard, we had in mind the most frequent carers according to European statistics - women of pre-retirement age (50-64 years) who are most likely to take care of older people and/or people with disabilities. **The whole manual in front of you is therefore tailored to the use of Facebook.**

1.1.1. Core groups

Resil4Care core group is a small group made from several members with diverse knowledge and experience in the field of care. The purpose of the core group is to jointly lead and moderate a larger online support group and to jointly create new content for informal carers. At the same time small core groups serves as a learning and support group to its members and thus provides the engine of the model, ensuring the sustainability of the process.

One part of the team is made up of care professionals, with **2-3 experts** per one core group. The main tasks of the experts in the core group are:

- supporting the work of the core group and content of the online support group with specialized knowledge in the field of care,
- indirectly identifying the needs of informal carers (through literature reviews, research and work in the field of care and trough contact with members of the online support group),
- controlling the quality and ensuring the validity of the information provided to the online support group,
- online group content creation - in cooperation with the other members of the core group,
- moderation of the online group (focusing on appropriate communication, privacy and ethical issues) - in cooperation with the other members of the core group,
- answering questions within the online group - in cooperation with the other members of the core group,
- others.

The other significant part of the core group consists of **2-3 informal carers** who have current or previous experience of caring for a family member or friend. Their main tasks are:

- integrating personal experience of caregiving in the work of the core group and in the content of the online support group,
- indirectly identifying the needs of informal carers (through own experience, personal contacts with other caregivers and contact with members of the online support group),
- online group content creation - in cooperation with the other members of the core group,
- moderation of the online group (focusing on appropriate communication, privacy and ethical issues) - in cooperation with the other members of the core group,
- answering questions within the online group - in cooperation with the other members of the core group,
- others.

As mentioned, the core group is like an engine behind the larger online support group. The members of the core group **should meet regularly** to create new content for the online support group during the meetings. It is recommended that the smaller group meets at least twice a month to ensure a good quality of work. At least one meeting of the core group should be held in person to allow the group to bond and get to know each other better. Other meetings could be held online, making it easier to coordinate allowing more flexible working.

In the group, we are all learners and all teachers. Each member's contribution is appreciated, as he/she brings his/her own experiences and knowledge to the group work. Each member has a role to play in the group. Roles can change or switch between members throughout the process - for example, someone is responsible for taking minutes of meetings, another for posting social media posts, etc. Before you start the work with the core group, it is important that someone in the group takes on the **role of the core group leader**. His/her main task in the core group are:

- to organise regular meetings of the core group,
- to lead the meetings of the core group and during the meeting ensures the rules of good communication, keep the timeframe,
- to manage the division of work in the core group,
- to supervise the work carried out,

When working in a group, basic rules for good communication should be respected:

1. Listen carefully to everyone, do not interrupt him/her with your story.
2. Talk only about the chosen topic.
3. Do not judge whatever one says, his/her views or experiences, but try to respect them as his/hers.
4. Whatever personal is said in the group, should stay there. Do not talk about the people who are not present or on their behalf nor about the things you heard and could be harmful.
5. When addressing someone use his/her name.

The small group works according to the in-group social learning methodology developed at the Anton Trstenjak Institute in Slovenia.

In-group social learning method

In-group social learning is an innovative group learning method based on the sharing of participants' personal experience and knowledge. It was developed by prof. Jože Ramovš, the founder of Anton Trstenjak Institute. The method is based on gerontological knowledge on ageing, anthropological knowledge on intergenerational relations and psychological knowledge on importance of experience sharing.



In-group social learning is a group learning method based on the narration of personal experience and personal knowledge of each participant, moderated by a group leader. The method focuses on positive experiences and includes only negative experience that were successfully resolved.

It builds on the human ability to experience empathy and solidarity toward others and in turn, develops these two characteristics further. One of the most significant advantages of in-group social learning is a bidirectional link between theoretical knowledge and actual living situation—skills and knowledge needed by participants are simultaneously transferred from and to everyday practice, helping participants to further understand their needs and possible concrete solutions.

Goals of the method are:

- development and shaping of human personality,
- quality intergenerational and other interpersonal relations, and
- encouragement of dialogue within families, working environments and on a societal level.

The Resil4Care model implies that the in-group social learning methodology is applied both in the work of the smaller core group as well as more broadly in online support group.

CORE GROUP

Core group = the engine behind the larger online support group.

Core group members: 2-3 professionals in the field of care, 2-3 informal caregivers.

Main focus of the core group: bringing together the care expertise and personal experiences of informal carers to jointly run and moderate an online support group and create informative and relevant content for informal carers.

Work of the group: core group should meet regularly (2 meetings/month, at least one in person, one online) to plan work, divide tasks and collect ideas for new content.

Methodology: In-group social learning

Worksheets

During the project, we prepared **worksheets** that can help core groups with their work. One worksheet served for at least one meeting for the core group while longer worksheets were divided into more parts. Resil4Care worksheets enable clear structure of work, provide interesting new topics for debate, encourage to make the core group more connected and overall serve as a good starting point for posts in online support group.

Worksheets cover a variety of topics, which can be divided into a content and a technical section. In the first months of the group, the topics are more focused on basic topics, both in terms of content (e.g. who are family carers, what are their needs) and in terms of technical issues (e.g. how do I set up a Facebook group, who do I invite to the group, how do I set the rules of the group). As the months pass and the group continues with its active work, the topics of the worksheets are further developed and enhanced. The worksheets are attached in the annexes to this document (from page 25 onwards).

Worksheets focused on the technical aspects of working with the online support group:

- WORKSHEET 2: How to set up a Facebook group 1.
- WORKSHEET 3: Group rules.
- WORKSHEET 4: Who to invite into a group.
- WORKSHEET 5: Carers' resilience and supporting carers through Facebook.
- WORKSHEET 5.1: Exercises on how to support carers and posting on FB.
- WORKSHEET 6: Inviting people into a group, bringing together different faces of care, how to care for one-self.

Worksheets focused on content for the online support group, tailored to informal carers needs:

- WORKSHEET 1: Who are family or informal carers and what are their needs.
- WORKSHEET 7: Practical information can strengthen the resilience of informal carers.
- WORKSHEET 8: Participation and family care through the camera's lens.
- WORKSHEET 9: Family carers' resilience.
- WORKSHEET 10: Why joining a support group?
- WORKSHEET 11: Self-care is important – for me and for the person I provide care to.
- WORKSHEET 12: Approaching the end of life, death and mourning.
- WORKSHEET 13: Holidays.

Topic in form of worksheets served as the basis for the core group work. It is very important to keep the purpose of the in-group social learning methodology (we are all teachers, all students) in mind and to work with specific selected topics (can be also others than proposed through the worksheets prepared as part of this project) taking into account our personal knowledge and experience in the field of care, while at the same time keeping an eye on the members of the wider online support group and identifying informal carers needs and wishes through the posts in the group.

1.1.2. Online support group on social media

Online support group is a larger group on one of the social networks (Facebook, Instagram, etc.) which is specifically dedicated to support informal carers online.

The main goal of such online support group is to improve resilience of informal carers and to enable them to help each other as well. Caring for a loved one is a demanding but important life task that can also be a valuable source of learning solidarity, deepening relationships and personal satisfaction. Nevertheless, caring for a loved one can also be very demanding and exhausting at

times. At that time, it is very important for informal carers to seek help from other close ones, as well as wider professional help. This large group of people seeks help and support in a variety of ways. Some like to call the carers helpline, some ask for advice from the community nurse, others use the web browser to ask care related questions. What most carers have in common is that they usually want to be in contact with other carers, as this way they can gain a lot of useful information and first-hand experience. Some also join carers in person support groups for this purpose.

It is important to maintain and develop new ways of supporting informal carers, as different ways of providing support to informal carers allow a greater adaptability to the individual, his/her habits and personality traits. For this reason, the Resil4Care partners wanted to add one more activity to the wide range of support activities for carers - online support groups.

The online support group offers support to informal caregivers by sharing up-to-date and current information and innovations in the field of care, explaining theoretical knowledge and sharing practical examples and demonstrations. For some informal caregivers, this knowledge and experience is currently relevant, while others in the group can gain knowledge that will come in handy when they are (again) in the role of caregiver. Asking care related questions in the group is also highly recommended. Sometimes a core group answers them through stories and practical examples, which allows group members to feel less alone in their role as caregivers, while at the same time reminding them that in caring for others, it is first necessary to take care of yourself. The group also enables informal carers to connect with each other, share experiences and support one another, which is one of the greatest benefits of this form of support.

Advantages and potential traps of online support group on social media

A support group placed in an online environment brings many advantages. Some of them are:



- new support channel for tech-savvy family caregivers and a new way to reach the target audience (informal caregivers),
- exchange of experiences from one caregiver to another,
- access to concrete, practical and up to date information,
- fast information flow,
- others.

Especially due to the online environment of the online support group, this option is very good for those informal carers who come from remote rural areas or simply have too much time pressure to join an in-person support group for informal carers. However, there are certain disadvantages and dangers of using support groups indiscriminately. We would especially highlight the following:

- negative attitudes towards social networks and the consequent non-use of these,
- poorer presence on social networks of persons with a lower socioeconomic status,
- poorer presence on social networks of the most burdened informal carers,
- negative communication on social networks (disrespectful, impatient, passive-aggressive communication of some social networks users),
- impersonal approach and lack of physical contact in social network groups,

- poor responsiveness of social network users,
- others.

Taking all that into account we should be careful not to underestimate nor overestimate the potential of social media support groups. If we work with the realization that this form is just one of the forms, we can use to support family carers and that as such it will not reach all the carers but will present the opportunity to some of them, social media presents a valuable new channel.

online (Facebook)
SUPPORT GROUP

Online support group is a new form of support for informal carers.

Online support group members: informal carers (and anyone interested in the subject).

Main focus of the online support group: The group provides up-to-date information and materials connected to the different aspects of our caregiving role. In the group informal caregivers can share experiences with others, give support, ask questions about caregiving or gain some additional knowledge that they may need in the future.

Work in the online support group: The online support group is facilitated and moderated by a smaller core group that provides informative and relevant content for informal carers, identify their needs and answer to their care related questions.

An online support group can be **open** or **closed**, depending on our wishes and the purpose of the group. The main advantage of the open online support group is that it offers greater reach on the social network and indirectly better possibility of informing and raising awareness about the family caregivers themselves. On the other hand, a closed online support group has other advantages, especially more intimate environment and with that deeper conversations, greater level of trust and consequently also more active and lively participation and interaction with group members.

If we want to really help and support carers through our online support group, we need to make sure that we offer them something concrete. We need to be careful that the support group maintains its purpose over time. We want to maintain its quality and develop it over time according to the needs of its users. It is important to cover as wide a range of topics as possible and to think about how to deliver them.

Posting in online support group on social media

Group posts can be tailored to meet the needs of users, particularly in terms of the **type of the post** and the **content of the post**. There are several types of posts on a social network like Facebook:

- text posts,
- photo posts,
- video posts,
- link posts,
- survey posts,
- live video,
- other types.

Informal carers face a variety of challenges throughout their caring experience, so it is appropriate that the content of the group is also diverse. The most relevant topics recommended for posting in the online support group for informal carers are:

1. Educational, informative content.
2. Practical content and technical demonstrations.
3. Personal experiences of informal carers (stories).
4. Content focused on self-care.
5. Other content (cultural content, invitations, etc.).

Educational, informative content for example covers a wide range of professional topics in the field of care, which can be roughly divided into:

- general information about care (national and international statistics about the carers, the different stages of care, different roles of informal caregivers etc.),
- information on new developments, political and legal changes in the field of care (in a national setting, and elsewhere in Europe and worldwide),
- legal, financial, ethical and other issues (what state aid I can get as an informal carer, what my care-recipient is entitled to by law and other important questions),
- media publications relating to care topics (the importance of information and awareness-raising about carers and their needs!),
- invitations to events that may be of interest to carers (invitations to participate in courses, workshops, expert lectures, research, self-care events, etc.),
- other care related topics.

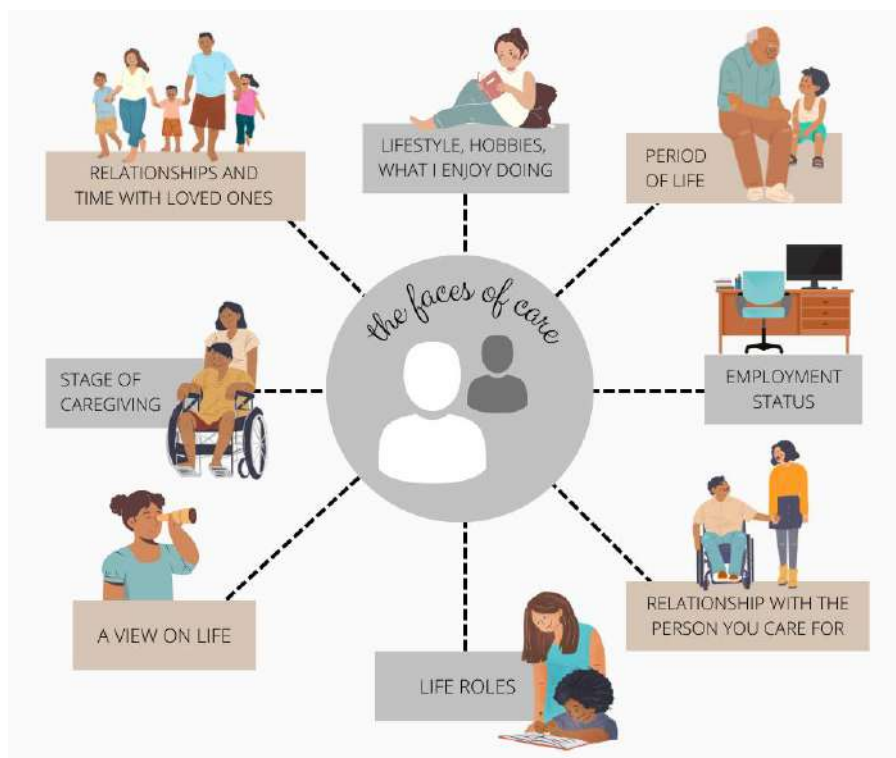


Figure 1: An example of educational, informative post in the online support group (prepared by Slovenian partner IAT).

Practical content and technical demonstrations include varied care related content to support carers from a practical point of view, for example:

- specialized theoretical content on care (e.g. communication techniques for people with dementia, information on specific diseases and conditions common in care recipients, etc.);
- presentation of home care equipment and devices (e.g. advice on adapting the living environment for better and easier caregiving, advice on choosing the right home rehabilitation aid, demonstrations of specific aids (e.g. sitting boards, fall sensors etc.);
- presentation of national services in the field of care (e.g. home care providers, additional home care services - pedicure, hairdresser, etc., presentation of support activities (day stays for the elderly, temporary stays in care homes), etc.
- presentation of national and international organizations in the field of care;
- other practical topics.

Personal experiences of informal carers represent real personal stories of people who are currently caring for or have cared for a loved one in the past. Having in mind in-group social learning method, we focus on positive experiences and include only negative experience that were successfully resolved. The content of the stories can be of a general nature, or they can focus on a specific topic within caregiving (e.g. my experience with communicating with a frail loved one, my experience of adapting to a home environment, how I balance care, work and personal life). Stories can be drawn from core group members own caregiving experience, found online, or gained through online support group members and through working or socializing with other informal carers.

Content focused on self-care is the next important group of content for the online support group. Informal carers often need an extra reminder and encouragement to take good care of themselves first when providing care for others. Self-care is important not only for informal carers well-being and resilience but also for the people around them and for quality of work and care. With content related to self-care, we want to help reduce negative feelings during caregiving, prevent burnout and highlight the importance of caregivers' physical and mental health. Content related to self-care should be holistic - covering all human dimensions (physical, psychological, spiritual, social, developmental, and existential human dimension). Self-care topics in online support group should be therefore varied - from ideas for easy sports activities, quality home-cooked meals and tips for good sleep hygiene, mindfulness practice, ideas for new hobbies that might interest us, reminder to seek help and share care for loved one, encouragement to turn on the lights - to actively look for the good in others, ideas for positively oriented books and movies, and other.

Other content in online support group includes other relevant topics that may be of interest and use to informal carers, for example:

- presentations of books, films or YouTube clips related to caregiving,
- ideas for joint leisure activities for carers and care recipients (coloring mandalas, writing memories of days gone by, participating in virtual tours of museums and mountains etc.),
- presentation and invitations on our organization's other care-related activities,

- sharing meaningful quotes and poems,
- greetings on national holidays,
- other ideas.



Figures 2 and 3: On the left, an example of self-care focused post in the online support group (prepared by Slovenian partner IAT). On the right, an example of another post in the online support group (prepared by Slovenian partner IAT). The graphic was accompanied by a link to many websites of national and international museums offering virtual tours.

Members of the core group all contribute with ideas for new topics, like interesting facts, policies, news, invitations, books, movies and other content which could be of interest to informal carers. Worksheets can also be a great help in creating new content for online support group. Within the group, members agree whether the content is suitable and prepare it for posting on social media. You can also ask online support group members for ideas and wishes on a specific topic. It is recommended that some content is also prepared in collaboration with other care professionals (like physiotherapists, occupational therapists, nutritionists and other) so the content is truly relevant (informative, practical) for carers and verified by professionals.

When preparing material for posting, group members follow the basic guidelines for posting on social networks. For example, Facebook allows you to choose the background text, add emojis or feelings, share a location, add a picture or GIF and other options. In addition, group members can also use other post design software to make their posts even more visually appealing and interesting for group members. If we go the extra mile for our social media post, this could prove to be a way to improve participation in the group and raise the profile of your group or the organization associated with it (especially if you add, for example, a company logo to your posts).

It is advisable to make posts to the online support group as regular as possible. Consistent posting schedule enables the core group to gain and maintain audience engagement and visibility on Facebook. Consideration of Facebook algorithms is also important as algorithms prioritize posts that earn more engagements (likes, comments, shares). Consistency of Facebook posts in the group helps build anticipation and might encourage users to engage more.



Here are some content recommendations for posting in the online support group on social media:

- **The content should be up-to-date and informative.**
Content should not be an end in itself. Before we post anything, let's ask ourselves: does this content serve to help and support informal carers?
- **Include first-hand experience in your social media posts.**
Include stories from real informal carers in your publications. Through stories, group members can find themselves in someone else's story and through this realize that they are not alone in this. You can even run a story writing competition on your online support group to collect new stories - be creative.
- **Practice > Theory**
Many people find and learn theoretical knowledge easily online. But most people don't know where to look for practical information, such as how to bathe your bedridden relative. Look for videos on YouTube and support the videos with explanations in your own language.
- **Include positive messages and quotes.**
Providing care is a challenging task in itself. Let us not burden carers with more difficult topics but encourage them to see the meaning and positive aspects of their caring role.
- **Connect with other organizations.**
Making a social media post can be a great opportunity to network with other organizations in the care sector. You can showcase the good work of another organization in a social media post or simply share one of their posts (e.g. an invitation to an event).
- **Go the extra mile.**
Try to find special content for group members (informal carers) that are otherwise hard to find. Maybe you can translate material that does not yet exist in your language or make an informative video yourself. These social media posts are very helpful and well received!

Here are some technical recommendations for posting in the online support group on social media:

- **Social media posts should be regular.**
Consistent posting on the social media helps the online support group to gain and maintain engagement of the group members and visibility of the group on Facebook.
- **Use different ways of posting on your social network.**

Some people are more visual, some like to listen to podcasts and others like quotes that they can save on their phone. Follow the reactions on your posts and adjust the type of post according to the reactions. It is recommended to use as many different options as possible.

- **Do your best to make your post look good.**

Your post will be less attractive if you only use text or a link to a website. Use the various options offered by the social network (different fonts, backgrounds, etc.) or use a special design software to edit it.

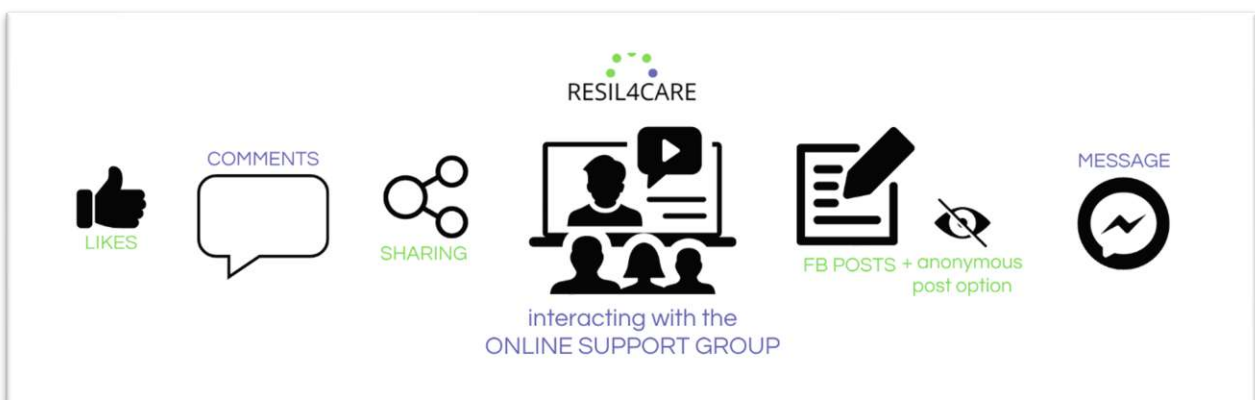
- **Maintain regular contact with online support group members.**

Don't forget to reply to messages and comments from the members of the online support group. This will give informal carers a new place where they can be heard and understood. From the point of view of your core group, direct contact with members of the online support group can also give you new ideas for topics and posts in the group.

Interaction with informal carers in online support group

As already mentioned, interaction with the members of the online support group is very important. Honest and positive feedback from online support group members tells us that the group is successful and serves its purpose. Our goal is achieved if we help and support family carers in their caring role through the help of the online support group on social media.

Online support group members can interact with all the options offered by their chosen social network. In the example of Facebook, group members can respond to posts by liking, commenting, sharing posts and private messaging the group moderator. Group members themselves can also actively participate in the online support group by making their own posts or sharing other posts and invitations to the online support group. Facebook also provides an anonymous posting option, which is ideal for those group members who do not want to expose themselves.



However, regular interaction with group members on a social network is a difficult task. Social networks are inherently designed to allow us to remain as inactive as possible and just be a kind of silent observer. They even allow the possibility of anonymous posts, but there are also other ways in which we can disguise our identity to a large extent and not expose ourselves online. Fundamentally, this is good and safer, but if we want to reach a lively and active group, it can also be a disincentive.

1.2. TRAINING

For successful implementation of RESIL4CARE model we carried out the training. The training itself was divided into two parts: we started with the basic training of core groups in Ljubljana followed by continuous training during the year.

1.2.1. Training in Ljubljana

RESIL4CARE training for informal carers and professionals took place between 3rd and 5th October 2023 at the Anton Trstenjak Institute of Gerontology and Intergenerational Relations in Ljubljana, Slovenia. The participants (22 in total) came from all partner countries: Greece, France, Italy, Spain and Slovenia. Each partner country sent at least two professionals in the field of care and two informal caregivers who formed into a new small core group at the training event to learn and develop for future work.



Figure 3: Work plan RESIL4CARE training for informal carers and professionals (Anton Trstenjak Insitute archive).

The objectives of the RESIL4CARE training for informal carers and professionals were:

- ✓ To understand **diversity and needs of family carers**, to learn and contribute into how to support them and to support them through social media.
- ✓ To gain **knowledge on how to set up and run an online (Facebook) support group** for family carers with at least 80 members in each pilot country.
- ✓ **To form and be a part of the core group** (made up of 2 professionals and 2 informal carers) that will meet regularly in order to “run” (administer, moderate and support with the materials) the Facebook page for the duration of the project and after.

- ✓ To learn **how to prepare different types of materials for the Facebook page** (written, photo, audio, video), to prepare them and to exchange some with the core groups of other pilot countries.

The workshop for informal carers and professionals was led by Ana Ramovs (from Anton Trstenjak Institute, Slovenia – Resil4Care partner leading PR2) and Alexis Lacapelle (from Interactive 4D, France – Resil4Care partner leading PR3).

The training was delivered in various ways – via lectures, working in small national groups (core groups), learning from demonstrations and discussing things together. The majority of activities that were carried out in the training used step by step approach. At the end of each session, all participants came together to present their work in small groups and discuss the content. The basic principle of the work on the RESIL4CARE training for informal carers and professionals was: we are all learners and teachers at the same time, which is the main guiding principle of in-group social learning method which was also used during the project's follow-up, working in core groups and in large online support groups for informal carers.

The first part of the event was dedicated to the basics that were needed to fully understand the topic and further develop the work of the project and in a further phase also for developing the RESIL4CARE training course manual and online materials for better resilience of informal carers.

INFORMAL CARERS

The first fundamental topic are **informal carers** themselves. Who are informal carers, how many people are in this role, who do they take care for, what kind of care do they provide? How do informal carers cope with their role and what are their own needs?



Informal of family carers are people – relatives, neighbors, friends – who provide regular care to someone with a chronic illness, disability or other long-lasting health or care need, outside a professional or formal framework. In Europe, 80% of Long-Term Care is provided by informal carers and their contribution is crucial for sustainability of care. Everyone can be in a role of informal carer at one point of their life. And while caring for someone can give a lot it can be also very demanding.

Sometimes the caregiving journey starts suddenly, even overnight (for example, when a loved one breaks a hip and needs immediate help with basic needs), sometimes it develops gradually over

time (e.g. as a loved one's chronic illness progresses). During the caregiving journey informal caregivers face many new changes and challenges on a daily basis so the role of the carer may also change over time. Experts in the field of care (Eurocarers, 2022) divide caregiving process into six different stages:



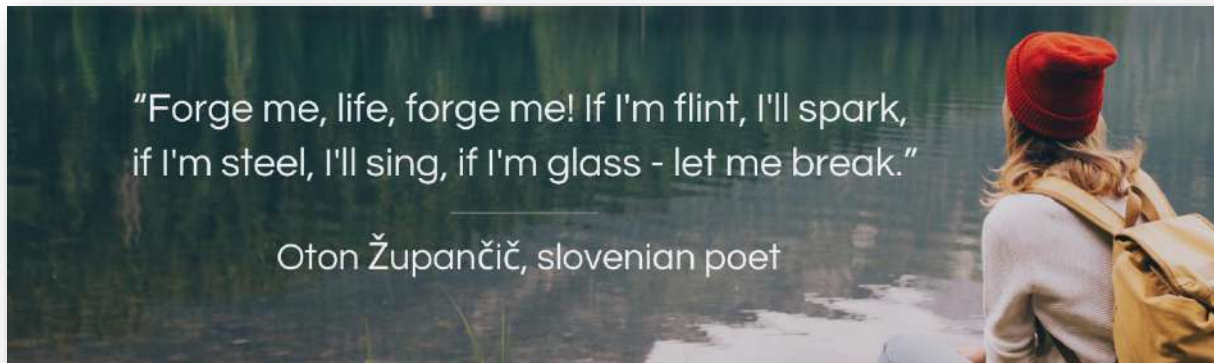
Figure 4: The stages of caregiving (Eurocarers).

Despite the frequent changes, informal caregivers grow and strengthen in their knowledge, practical experience, relationships and personality through the process caregiving. They gradually lose their fear and gain more confidence in their abilities. Over time and experience, they become more and more resilient within their caring role and in life in general.

RESILIENCE

Resilience is the process and outcome of successfully adapting to difficult or challenging life experiences, especially through mental, emotional, and behavioural flexibility and adjustment to external and internal demands. Resilience is also defined as:

1. the capacity to recover quickly from difficulties; toughness.
2. the ability of a substance or object to spring back into shape; elasticity.



SOCIAL NETWORKS FOR ONLINE SUPPORT GROUPS FOR INFORMAL CARERS

Other fundamental topic for participating in RESIL4CARE training for informal carers and professionals in Ljubljana and all the other subsequent project activities is **understanding and working with social networks for online support groups for informal carers**. In the Resil4Care project, we chose Facebook as our main social network because we assumed that it was the most used social network among our target audience (informal carers).

During training, informal carers and professionals renewed and/or upgraded their knowledge on:

- What is Facebook?
- How to create and manage a Facebook account?
- How to start a Facebook group?
- How to invite friends into Facebook group?
- How to manage security and settings on Facebook?

Informal carers and professionals in the training firstly looked at an example of a Slovenian online support group that already exists, then they continued with their work in small national core groups. Following a step-by-step approach each core group started their own Facebook support group after which they started to develop the first content since the quality content is one of the necessary 'ingredients' of successful social media support group.

The work was carried out through a variety of exercises from the topics informal carers and professionals just learned or renewed their knowledge. Exercises were later incorporated into the first worksheets, which are attached as annexes to the document.

- EXERCISE 1: Present yourself as a group (see Annex 1: Worksheet 1)
- EXERCISE 2: Sharing a video about care (see Annex5: Worksheet 5.1)
- EXERCISE 3: Gratefulness (see Annex5: Worksheet 5.1)



Figure 5: First meeting of the Spanish core group on training event in Ljubljana (photo: Ajda Cvelbar).

1.2.2. Continuous training

After the training in Ljubljana, we continued with the work in core groups. To ensure their success, we have also continued to provide continuous training for all the core group leaders from each partner country. Every month for more than a year we held an 1,5 hour long online international core group leaders' meeting on Zoom platform.

The aim of the continuous training was to mitigate new challenges in the time core groups were facing them, to learn from each other successful experiences and to add new knowledge on how to lead small core group and bigger and bigger online support groups. As mentioned above, the method that enables this type of learning from each other and combines theory with practice, is in-group social learning method.

Majority of the continuous training was dedicated to the **experience sharing**. In practice, during each session each core group leader shared their experiences of leading the small core group over the last month, impressions from running a larger online support group, talked about relevant new topics and shared good experiences and challenges they were facing. When problem arised, other members were encouraged to share their experience of solving similar problems in their respective countries thus enabling all to learn from each other's good experiences or those bad experiences that were successfully resolved. For example, if one of the group leaders (together with her/his core group) had problems attracting new members into the social media platform the rest of the core group leaders shared their experience helping the group leader who was facing an obstacle to think about different possible practical solution. A similar round of sharing was carried out if one of the group leaders encountered a very important or challenging topic.

The rest of the meeting was dedicated to the **topics important for leadership of the core groups or topics that arised from the first part of the meeting**. Those topics were:

- Topics regarding successful leadership of the core group – group that is meeting in person (on how to lead a group, on importance of regular meetings, on communication culture, on what happens if someone leaves the group etc.)

- Topics regarding successful moderation of the social media support group (on topics important for informal carers, on importance of diversity of posts in topics and mode of posts, on interactions with online group, on how to invite new members etc.)
- Topics that arised during the meetings (on working with and understanding informal carers, what to do when informal carers are too busy to participate or work on their 'homework', on how to deal with a member who lost their loved one – care recipient, about grief ect.)

Continuous training meetings were moderated by a professional with experience of leading different types of groups and working with social media.

During the meetings, the core group leaders from each partner country gained new knowledge, which they later shared at their separate core group meetings. They were also given new worksheet that they could used during the next two core group meetings. The Resil4Care **worksheets** are prepared in a way, that leads the user (group leader and groups members) through the process of starting their own group and at the same time starting and moderating bigger online support group. It helps the leader to keep the group meetings structured and meaningful for the members giving them conversation topic. At the same time it is prepared in a way that it helps to 'generate' posts that can be than used on social media by providing tasks for the members. Those tasks can be carried out either during the meetings or in the form of homework for all the members.

Combining training in Ljubljana and continuous training, core group leaders and other core group members carried out more than 24 hours of theoretical knowledge training and did more than 36 hours of practical work (in form of regular core group's meetings and working on the tasks predicted by worksheets).

Continuous training was of great added value for Resil4Care project, as it allowed the core group leaders (and consequently all the members of the core group) leading the online support group from different countries to share the rich experience and knowledge they had gained during the process. We also suggest that other potential users of this model seek further training and consultation with other individuals or organisations already running online support groups on social media.

1.3. LESSONS LEARNED

1.3.1. Working in core groups

Working in core groups has proved to be highly valuable. The group provides a space to share professional and personal experiences in the field of caregiving. Meeting for more than a year, groups connected within themselves and formed their own identity, being – beside knowledge hubs – small support groups for their members.

Tips and tricks: It is very important for the core group leaders to realize that they are leading two types of groups while working with the model. For successful work with social media it is important that small core groups (engine) runs well and enough attention has to be given to working with the core group and their members. Things to be observed while running a group are:

- Keep regular meetings with schedule known in advance, if possible, at least two times per month. Since less frequent meetings make it harder for group to connect and work well.
- While some meetings can be more relaxed in structure it is important for majority of meetings to be well structured, thus giving the meaning to the meetings. Structure also means safe space for people to be able to share things important to them.
- Be structured, but be also flexible: if important topic arises, especially if something really difficult or joyful happened to one of the members and this member decides to share that within a group, attention has to be given to this member and this topic. Reacting of group leader in these situations is especially important. General rule that can help you is to share the joy with happy and sadness with sad. Don't try to fix the problems that are too difficult to be fixed instantly and don't try to make a moral out of it – listening and sharing similar experiences is enough and can bring more comfort to the group. On the other hand, if occasion call for celebration, celebrate!



Figure 6: Members of the Slovenian core group (photo: Ajda Cvelbar).

1.3.2. Working with in-group social learning method

The in-group social learning method, which allowed every member of the group to be equally heard and important, also proved to be highly recommended. The method was also applied within the FB

group, where the "all teachers, all learners" approach was applied to the recommendations and ideas of the group participants equally. Their suggestions or perceived needs were debated within the core group and developed into new topics for posting within the group, where they also benefited the other participants. Also, within the online support group, we have encouraged members to share their good experiences of caring, or well processed bad experiences, which is the basis of in-group social learning method.

Tips and tricks:

- Observe good communication rules (page 6). It is important that each member is given a space to share their experience and voice their opinion. At the same time, it is important that while doing that respect to the people not present and present members is observed.
- It is important to be attentive to group members: to thank them for their contributions, to notice if something important is happening in their life, to remember their birthdays and send them a congratulatory card or message for their holidays etc. Members give valuable contribution to the group and they should also receive something (support, companionship) from the group.
- While discussing different topics it is important that group leader also participates as group member, sharing his/her own experience. In few places mentioned principle 'we are all teachers and all learners' means that all the members have something to contribute and that we all have something to learn. Furthermore, while group leader is in charge of organization and he/she leads the structure of the meeting, shared experience on topics are personal, so it is important group leader also contributes. Finally, it is important that group leader also observes good communication rules, not judging the experience of others but thanking each member for their contribution, maybe emphasizing something good or topic related from the experience that was shared and connecting all the experiences.

1.3.3. Working with the worksheets

Worksheets are a tool that helped with the step-by-step formation and consolidation of the core groups and social media groups, helped with the structure of the meetings and provided the materials for the posts. As such they were recognized as valuable by all core group leaders. The most recognised challenge of working with worksheets was their length, as some of them turned out to be too long. Members of the groups sometimes reported that they had insufficient time for completing the worksheets. So it is important to give enough time for more time consuming tasks and to also understand the situation of informal carers. For example, if situation of informal carer who participates in the core group becomes very demanding at certain period of time and she/he can not follow the tasks, it is important to adapt the number of task allocated to that member or to include her/him only in tasks that can be done during the meetings; on the other hand we have to pay attention not to exclude such member from the tasks as this might give them a feeling of abandonment..



Figure 7: First meeting of the Italian core group on training event in Ljubljana (photo: Ajda Cvelbar).

1.3.4. Online support groups

ADVANTAGES of online support groups

We have found many benefits of the online support group for informal carers. The first is that the online form of support brings a new option for some carers who are comfortable with this format.

The group also has a wider purpose - because the group grows through new members and can appear to other users of social networks, it is also of great importance for raising awareness about informal caregivers and their needs. This is especially important in countries where this group is not yet recognized or mentioned in local and national media and politics.

CHALLENGES of online support groups

What is on the one hand the group's greatest strength can on the other hand also be a weakness. Many carers do not use online platforms and are therefore often not interested in starting to use them. Some people don't feel skilled enough for using online networks, while others find online networks a waste of time. Resil4Care project foresaw this, which is why we have dedicated a special part of the project to developing an educational platform for informal carers who would like to improve their social networking skills.

The social platform itself also brings certain challenges. Nowadays, a kind of passive behaviour is quite common on the networks that shows in only reading the posts on the platform with very small number of actual content contributors in the platform. This limits the diversity of contributions, as well as the quantity and speed of answers to informational or emotional support questions posted to groups and forums. If an online support group is not active, it can quickly die out.

3. ANNEXES

Annex 1: Worksheet 1

Dear core group members,

This exercise will serve as an introduction to this morning session. You will be invited to read the questions on the next page and translate them into your language. Each member will have around 2-3 min of time to think about the answer, then you'll share your answers.

In the group, we are all learners and all teachers. Each member's contribution is appreciated, as he/she brings his/her own experiences and knowledge. For satisfaction of all participants in the group, ten basic rules for good communication should be respected: 1. Listen carefully to everyone, do not interrupt him/her with your story; 2. Talk only about the chosen topic; 3. Do not judge whatever one says, his/her views or experiences, but try to respect them as his/hers; 4. Whatever personal is said in the group, should stay there. Do not talk about the people who are not present or in their behalf nor about the things you heard and could be harmful. 5. When addressing someone use his/her name.

Before you start the work, decide who will be the group leader. Please choose the person (professional) who will also participate every 2-3 weeks in international zoom meetings. Please also choose a person that will take notes during sharing and report them during the presentation of the groups.

The role of the leader is to:

- Invite everyone to start working on the question, taking few minutes to think.
- After few minutes of silence, the role of the leader is to invite everyone to share their thoughts. The leader of the groups starts himself/herself by sharing the answer to both questions.
- We advise the leader than gives the word to the person on his/her left. It is important to invite people to speak and to personally thank everyone who finishes speaking at the end.
- Take care to observe the rules of basic group communication that we just read.
- Take care of time.

The group leader is: _____

The person who reports is: _____

WORKSHEET 1: Who are family or informal carers and what are their needs.

First, think about different types of care. Think about people you know, situations you heard about. Who provides care to whom? What kind of care do they provide?

_____ (translation)

Think about your experience as family carer. What do/did you need during the time you were providing care? Think also about people you know (maybe the same you remembered before), what are their needs as carers?

_____ (translation)

Annex 2: Worksheet 2

WORKSHEET 2: How to set up a Facebook group 1.

Now, you will start setting up a Facebook group. This group will be your tool to help family carers. Through the group you can share information, encourage supportive discussion, tell people about useful tips for care provision, support them in their care for oneself, share useful lectures, etc..

Think about the name of the group. What do you want to call yourselves? What name will help people to find you?

Name of our group: _____

Think about how you will present care, support, your intention in picture or photo. Choose a picture or a photo that you want to present your group with.

Our chosen picture is: _____

Write a description of the group. Use the ingredients: who is the group for (who can join), what is the aim of this group (why did you set up a group, which topics will be present), for what kind of help can people come into this group, how can they participate (by writing private message, by writing messages to whole group, by commenting and answering), there are some rules they have to follow (we will talk more about the rules tomorrow, so today we just suggest you include this sentence into description).

Our group description:

_____ (translation)

Annex 3: Worksheet 3

WORKSHEET 3: Group rules.

Every group needs a set of rules, especially if they want to create supportive, respectful and positive environment. We don't want this support group to become a complaining group. Modern science shows that as adults we learn the most from good experiences of others. We are also able to learn from bad experiences of others but not so directly; logotherapy teaches us that most effective way to learn from bad experience of others is when other have already processed them and learned something from them. For those of you who like to garden, it is like with the compost – only when it is processed new things can grow from it.

The rules below were made in the interdisciplinary team with a lot of experience with group work after in-depth consideration.

Together with a whole group read the list of the rules below one-by-one. Translate them into your language so all members of the group can understand and reflect on them. Think if you need to add something or if in your context you need additional rules and type your own list of rules.

1. Exchange of information about the care provision and nursing.
While exchanging information about services and other options you discovered, please write down the location – that way it can be more helpful to other people.
2. Exchange of good personal experiences while providing care.
Good personal experience can provide motivation and support for people around us. Modern science shows that as adults we learn the most from good experiences of others or from those bad experiences that others already processed and learned something from. You are warmly invited to share one or the other. Please, use first person singular, when you share your experience.
If you decide to share good experience of another person, please make sure that person is fine with that and/or that he/she cannot be recognized from the story – please, protect privacy.
3. Discussion about care related questions and dilemmas.
While answering the questions please think about your GOOD experiences on the subject or solutions you found. Professionals will help to provide answers.
4. Reflection about long-term care, care provision and forms of support.
Please be constructive while reflecting about long-term care, care provision and forms of support. Even if you choose critical approach, please stay respectful.
5. Rules for good communication should be respected.
Write in a clear and concise way. Before you comment on somebody else message, read carefully what he/she really wrote.
6. Know how to keep your silence.

Imagine how will you feel, when your message will be read by people you know and by people you don't know. Before posting a message, think if your message could hurt somebody.

7. In group we don't.

In this group we don't criticize, insult, accuse others and post about themes that are not connected with care provision, support and long-term care.

Annex 4: Worksheet 4

WORKSHEET 4: Who to invite into a group.

Think about all the different types of family carers we talked about yesterday. Think about who are the crucial people or organizations that are in contact, what places do they frequent. Write them down:

Now think concretely, who, where and when can you reach. Write a plan. Do not forget about your personal contacts.

Annex 5: Worksheets 5.1 and 5.2

WORKSHEET 5.1: Exercises on how to support carers and posting on FB.

Exercises 2. and 3. day of training in Ljubljana

Exercise 2: Facebook post about GRATEFULNESS

Tomorrow is EU Carers Day. Think about how you can show and tell informal carers you appreciate their work, show them that what they do is important, that they do it well or to the best of their abilities.

Prepare Facebook post in which you can use different colours, bold or italic letters, emoticons, you can even add a picture or photograph. Make it beautiful :)

Then share the post from other partners. Always add an explanation for context, for example: We are currently in Slovenia in the Erasmus Resil4Care training about how to support informal carers. Our friends from _____ also expressed their gratitude ...

Exercise 3: Facebook post – VIDEO

- Look at the videos about care. What would be useful or interesting for your informal carers and why?
- Write 1-3 lines of text and add a video (link).
- Tell others how you feel about it (emotions) and post it.

Don't forget to check the videos from other partners posts and like/ comment on them.

WORKSHEET 5.2: Carers' resilience and supporting carers trough Facebook.

For this exercise it is especially important to work as a group.

- First translate both questions.
- Thank take 5 minutes time to think and write down your answers. After 5 minutes of silence, the role of the leader is to invite everyone to share their thoughts. The leader of the groups starts himself/herself by sharing the answer to both questions.
- We advise the leader than gives the word to the person on his/her left. It is important to invite people to speak and to personally thank everyone who finishes speaking at the end.
- Take care to observe the rules of basic group communication that we just read.
- Take care of time.

Think about your experience as family carer. If you don't have personal experience, think about the people you know. What, who and how helped you most when you were providing care? What, who and how made your care day easier?

_____ (translation)

Think again about your experience as family carer. If you don't have personal experience, think about yourself in difficult, stressful situation. Try to remember one concrete situation, when you coped well with difficult situation. Where, when, how and in what did you find your inner strength?

_____ (translation)

Annex 6: Worksheet 6

Please translate and read out aloud at the beginning of the group meeting:

Dear core group members,

Almost two months passed since our training in Ljubljana. We already met in our local core groups one time, some even more times. Let's start this meeting with stopping a bit and seeing where we are: in Ljubljana we talked about who are informal carers and what are their needs, we set up informal carers support Facebook groups and started to post there, beginning with introduction of our groups. We made a plan who can we invite into those groups and talked about resilience. Last month you mostly worked on inviting people into the Facebook group, some of you made plans that are underway and some even started posting. Now in December it is good time we liven up our support groups.

We propose, you start each meeting with looking back at what have you done from the last time you've met. After that you will get one to two questions to discuss on the meeting.

While discussing remember that in the group we are all learners and all teachers. Each member's contribution is appreciated, as he/she brings his/her own experiences and knowledge. For satisfaction of all participants in the group, five basic rules for good communication should be respected: 1. Listen carefully to everyone, do not interrupt him/her with your story; 2. Talk only about the chosen topic; 3. Do not judge whatever one says, his/her views or experiences, but try to respect them as his/hers; 4. Whatever personal is said in the group, should stay there. Do not talk about the people who are not present or in their behalf nor about the things you heard and could be harmful. 5. When addressing someone use his/her name.

Each meeting will also present you with a task. You can fulfill it together at the group meeting or you can decide to work on it each one separately at home. The result should be 3-4 posts that you will post till the next meeting. If you decide to work at home, make a concrete plan who will do what and till when.

We propose that the one in charge of collecting all the work done and posting at the beginning is the group leader; another equally good option is to divide the posting between yourselves. Whichever option you choose, it is important, that you discuss it and that all the members know who is posting prepared posts.

Finally, as we already discussed in Ljubljana, the group leader will be in charge of leading the meetings. The group leader will invite everyone to start working on the question, taking few minutes to think.

- After few minutes of silence, the role of the leader is to invite everyone to share their thoughts. The leader of the groups starts himself/herself by sharing the answer to one or both questions.
- We advise the leader than gives the word to the person on his/her left. It is important to invite people to speak and to personally thank everyone who finishes speaking at the end.
- Take care to observe the rules of basic group communication written above.

- Take care of time.

At the end of the meeting, set the date and time for the next meeting. Invite everyone to write it down. As we talked in Ljubljana, each group will meet every two-three week, so normally you would meet two times each month. And now, let's go to work!

Annex 7: Worksheet 7

WORKSHEET 7: Practical information can strengthen the resilience of informal carers.

Dear core group members! Happy New Year! How were your holidays? If this is your first time meeting this year, I would like to invite you to share your holiday experience with each other; make a small round and maybe each member can share something nice, one good thing they experienced during this festive time. I suggest group leaders starts with her experience and passes on the word to next person.

Now let us go to first topic of this year 😊 As we talked in Ljubljana's training there are different ways to support informal carers. One of them is to provide them information they need in simple, useful way. Provided answer can help, can save time and sometimes also save a lot of stress when people have to search for it!

1. Think about all the questions you had about care from when you started to provide care till now. What practical information did you need the most? Did you get or find the solution? Where did you get it from or who helped you? If you don't have your own experience of care, think about others around you. Write your experience on the paper. After that share it the rest of the group members.

2. Collect all the needed information you listed as a group in one place. Are some of them similar? Do some of them go into the same group of information? If yes, try to find the title for this group of information. Is there a group of information you think is essential for care missing? For this part of the exercise, you can use post-it notes to write down one information per post-it and then put them together into groups or you can write them all down on one paper and use different colours to combine them into subgroups.

As part of this exercise, I suggest you also watch one or two videos with practical information together. Did you find information useful? If yes, include them into the list you are making.

3. Finally chose 4-8 practical information and decide in what form do you want to present it to others on the Facebook forum; it can be in the form of written question and answer, it can be presented graphically, as a story, maybe you can share a link to the video with an answer, to the webpage etc. Divide among yourselves who will prepare what. Ideally each members takes one task (including group leaders) and more if they want. Don't forget to set the date till when you will each prepare a post or information for the post.

Annex 8: Worksheet 8

WORKSHEET 8: Participation and family care through the camera's lens.

Dear core group members! How are you doing? Those of you, who currently provide care to someone, how is the person you provide care for doing? Can you think of a good memory, something you experienced during the last few weeks, that was positive for both - you and the person you provide care for? Make a small round where each member shares something. As we talked during the last group leaders' meeting: only by listening to and supporting each other will our group be able to provide good support to bigger and bigger Facebook family carers' group. 😊

1. How can we help people in our Facebook group to be more active and to engage more with the group?

Take 15-20 minutes to think about possible solution. Think about what are your goals (Do you want to increase communication – comments, emoji reactions? Are there any other forms of interaction you can think of?) and discuss suggestions you have for improvement. Based on those suggestions, form some simple tasks and divide them between yourselves.

<p>What does Facebook participation mean for us – goals we want to achieve:</p>
<p>How can we increase participation – suggestions:</p>
<p>Concrete tasks – who will do what and till when:</p>

2. Family care through the camera's lens

There are different ways to present care and how do we feel about care to others – when describing it we normally use words, but we can also use photos and pictures.

Photography taking or drawing itself can be insightful exercise – for ourselves and others. While taking a photo or drawing a picture we have to contemplate the subject. What is care for me? Where can I see it? Is it in a person, in a gesture, is it hidden in an action, in an object? Is there something in nature that reminds me of my care experience? What kind of feelings does thinking about care and caregiving bring?

During the upcoming month I invite you to think about these questions and collect some impressions in form of photos and pictures. You can go about that in different ways (I suggest you choose two among them – one for each meeting, but of course you can also come up with your own way):

- Each group member can individually carry out the exercise. Ask yourself the questions above and try to take few photos. Under each photo write a sentence – short explanation or thought that crossed your mind while you took that photo. In the next meeting share your photos and thoughts with others. Together as a group you can choose a collection of photos and thoughts (maybe one or two from each person) that you will share on Facebook. Not all the photos have to be shared, you can also make some just for yourself or for the group to see.
- Ask people around you the above-mentioned questions and invite them to share one or two photos with you. You can also engage children and ask them to draw you a picture about care provision for someone. Complete these photos and pictures with short description of the person you got the photos or picture from (for example: teacher, 36 years old, with experience of providing care for a child or kindergartener, 4 years old, his mom is providing care for his grandmother). Share the photos and pictures with the rest of the group and together select photos for Facebook group posts.
- You can also do an exercise together. Take a one hour walk around the place you normally meet while thinking about the questions above. Try to take few photos. When you return to the meeting place, show photos to each other, and discuss the meaning behind them. Don't forget to select photos to post on Facebook at the end.
- You can also engage other people on Facebook, by encouraging them to share photos and pictures with you. Think about the best way possible to do that.

Annex 9: Worksheet 9

WORKSHEET 9: Family carers' resilience

Dear core group leaders and other participants! How are you doing? 😊 This time we will work in small national groups and ahead of us is a special mission: to prepare a short video about family carers resilience. We will do that by following few steps:

Step 1: Think about the training in Ljubljana and discussion we had about resilience there. The questions we discussed where: What, who and how helped you most when you were providing care? What, who and how made your care day easier? AND try to remember one concrete situation, when you coped well with difficult situation. Where, when, how and in what did you find your inner strength? **Discuss the questions one more time. How do you understand them now in the light of resilience definition written above? Write down few thoughts. 10'**

Step 2: Keeping in mind definition of the resilience, discussion in Ljubljana and what you discussed now, think about how you would present family carers' resilience to others in 3 minutes. So: What is resilience? How does it look in practice? Why is it important? Write down few thoughts. 5'

Step 3: Now write a 3-minute scenario where you explain to people What is resilience and why is it important, we talk about it. Remember to use simple language, practical examples. Your scenario can include also written key words or simple drawn pictures – be inventive 😊

Annex 10: Worksheet 10

WORKSHEET 10: Why joining a support group?

Dear core group members! How are you doing? Those of you, who currently provide care to someone, how is the person you provide care for doing? Can you think of a good memory, something you experienced during the last few weeks, that was positive for both - you and the person you provide care for? Make a small round where each member shares something. Maybe you can make it a habit to tell yourself this or something else that was positive and happened during the last two weeks every time you meet 😊 After you finish sharing let's start with today's special mission: to prepare a short video about our Facebook support group. Here are some steps that can help you with the preparation and filming:

Step 1: Think about your Facebook support group for carers. How would you describe it in maximum 5 sentences? Write those sentences down. 5'

Step 2: Think about the training in Ljubljana and the start of you Facebook support group for carers. Why did you join the Facebook group at the beginning? What were your expectations? What were your fears? Think also about other people who joined the group and you know. Maybe they had some concerns or fears? Did they know about the existence of the Facebook group and what the group is about? Write down few thoughts. 10'

Step 3: Now think about all the content and discussions in your Facebook support group for carers. What kind of the content is your favorite? Is there something that you especially like about the Facebook group? Maybe an option you discovered? Why concretely you find this group helpful? Write down few thoughts. 10'

Step 4: Now combine the steps 1 to 3 and write a 1-2-minute video scenario with the title: **I am a family carer / I am professional working with carers and I find this Facebook support group for carers helpful because...** You can do that in two different ways:

- each core group member can write their own scenario, after that you share written scenarios with each other and improve them in a group OR
- you can write the scenarios together after listening to first 3 steps of each member.

It is important that in both cases you have one scenario for each member of the core group.

Remember to use simple language, practical examples. Think about when and how will you record videos. It can be on this meeting or you can have a special meeting. You record the video with camera or your phone on the stand, inside or outside. You can speak freely or you can read. You can be each one alone or you make the videos in form of an interview. You can include also written key words that you show on the paper during video, props or simple drawn pictures – be inventive.

Annex 11: Worksheet 11

WORKSHEET 11: Self-care is important – for me and for the person I provide care to

Dear core group members! How are you doing? How was your summer? Those of you, who currently provide care for someone, how is the person you provide care for doing? Can you think of a good memory, something you experienced during the summer that was positive for both - you and the person you provide care for (or in case you don't provide care for anyone, something you experience with someone)? Think of a summer memory you hold dear or that made you feel better, made you laugh... Make a small round where each member shares something. Maybe you can make it a habit to tell yourself this or something else that was positive and happened during the last two weeks every time you meet 😊

After you finish sharing let's start with today's topic! We are all occupied with a lot of things: different types of work, activities we engage in, household chores that have to be done, children, maybe grandchildren and last but definitely not least, all of you who are family carers, with care provision. Among all these we tend to forget about ourselves. Slovenian professor Joze Ramovs says If you want to provide care for others you have to take care of yourself and if you want to take care of yourself provide help to others; implying that provision of help and care for others can help us grow personally but if we want to provide that care (and provide it well), we have to also take care of ourselves. Which makes self-care important not only for our well-being (which is very important) but also for the people around us and for our quality of work and care.

1. Look at the chart below. Read it together and stop at each human dimension to discuss what concretely do you (all members of core group) already do for yourself. Collect all your experiences in the right column.

HUMAN DIMENSION	SUGGESTIONS FOR HEALTY HABITS	CONCRETE EXAMPLES OF WHAT WE ALREADY DO
PHYSICAL (BODY)	<ul style="list-style-type: none"> - Make sure you eat a healthy and balanced diet. - Keep up a regular rhythm as much as possible (daily routines can help you). - Regular physical activity! Choose the one you can do and enjoy. - Get enough sleep, regular exercise and relaxation exercises. - Avoid too much nicotine, alcohol and caffeine. 	

<p>PSYCHOLOGICAL (MENTAL)</p>	<ul style="list-style-type: none"> - Relax and take time to find your daily peace. - Discover what causes you tension and pay attention to your reactions. - Forget perfection. - Cultivate bright and positive thoughts. - Laugh! 	
<p>SPIRITUAL (BELIEFS AND THINGS THAT ARE BEYOND US)</p>	<ul style="list-style-type: none"> - Be able to say NO when you can't do something, can't handle it or don't want to do it. - When you find yourself in a bad situation, ask yourself what could be worse. Accept the worst-case scenario in your mind and then find try to find a way out. - Some things are unchangeable or not dependant on you no matter how much you wish it. Accept the circumstances that you cannot change. - Make decisions that are achievable, otherwise it is better not to make them at all! 	
<p>SOCIAL (RELATIONSHIPS)</p>	<ul style="list-style-type: none"> - Light the lamp – try to actively search for positive in others! - Don't blame others for your tension. - Cultivate affection for all people. - Talk about your problems. - Avoid conflicts with other people. 	
<p>DEVELOPMENTAL (WHAT SUSTAIN US AND HELPS US GROW)</p>	<ul style="list-style-type: none"> - Balance work, leisure, entertainment. - Read good books. - Be selective while watching TV. 	
<p>EXISTENTIAL (WHAT GIVES US MEANING)</p>	<ul style="list-style-type: none"> - Find meaning in the things you do. - Appreciate what you and your loved ones have created and done well. 	

HOMEWORK:

1. **Write a short story about what do you do for yourself in this autumn months** – you can describe one thing or more things you like or find important. Write also why do you think it is important for you. Post the text with a photo (it can be yours or symbolic) in your Facebook

group and encourage other carers to also take care of themselves in this autumn months and to share their experiences.

2. **This month is dedicated to the dementia.** Dementia is one of the most common diseases among older people. It is difficult for people who get ill, for their family and for those who provide care for them. During this month share some information about dementia in your Facebook group. You can translate one of the videos from UCLA caregivers training course (<https://www.uclahealth.org/medical-services/geriatrics/dementia/caregiver-education/caregiver-training-videos>) and/or use something local.
3. **Resil4Care training platform is almost prepared.** Share the news in your Facebook group (with the information coming soon). Write down your experience in making the content. As soon as the platform will be ready, publish one or two videos that are already available and add the link to the platform, so your carers can try it out. ☺

Annex 12: Worksheet 12

WORKSHEET 12: Approaching the end of life, death and mourning.

As always, in the first round, let's look at how we are since we last met - has anything good happened, something that was good for both you and the person you provide care for? Has there been anything particularly difficult? Let's share one thought with others.

Autumn and winter are persistent reminders that our lives are fleeting. The fruit on the tree ripens and leaves fall off. And the winter that lies ahead, with its blanket, sometimes leaves the impression that everything has almost stopped - died. Yet each year also teaches us that something survives, and that nature, which has been asleep, rises in all its beauty with spring. Our loved ones, perhaps those we have cared for, have also left a piece of themselves behind. No matter what we believe, a piece of our loved ones lives on in our memory, perhaps in our knowledge, a good habit, in the strength to do something.

1. Today, let us first remember those who have passed away. How did they mature in the last period of their lives? What particularly spoke to us? What are the best things that they have left in our memory? Let us recall the concrete personal, if one of the people we cared for has died, we can recall them, or if all our cared-for are still alive and the thought is too difficult, we can recall someone else we knew well. In a few minutes of silence, let us remember with the help of the questions above and write something down. Then share with others the part we are most comfortable with.

2. Afterwards, write some thoughts about the deceased and what their memory means to us - they can be general, personal, anonymous or signed. The important thing is that we feel comfortable doing so. You can also choose a quote. Then let's see together if we can find a photograph that would go particularly well with what we have written.

Annex 13: Worksheet 13

WORKSHEET 13: Holidays

Dear core group members! How are you doing? Those of you, who currently provide care for someone, how is the person you provide care for doing? Can you think of a good memory, something you experienced since we last met that was positive for both - you and the person you provide care for (or in case you don't provide care for anyone, can you share a small moment that made you happy and you experienced it due to someone)?

Holidays are a special time for everyone. They bring back memories. They bring families together. They are often time of joy, light and plenty – time when we open our hearts a bit more to each other. But they can also be very busy period when care provision is even more demanding due to all the other tasks that we set ourselves to do.

1. So looking at the upcoming holidays, what can we do to really make these holidays peaceful and joyful for us and for others? Let's keep in mind, that busier period we have, more it is important, we also take time for ourselves. Look at the chart in the worksheet number 11 (self-care) and choose one or two things you plan to do during upcoming holidays for yourself. Share your plans with other members of the group.

Task: After you finish, together find a way to encourage your Facebook support group members to do the same.

2. ALTERNATIVE: Holidays can be also difficult time for some people, they can bring back memories of people we miss. And while there is plenty and joy for many, those who are alone or lacking kind human word feel it stronger than ever. Do we have any experience of being in such situation and someone helped us / made days better for us? It doesn't need to be only during the time of holidays, it can be also an experience of a regular time when we felt down, dejected. Let's write down our experience and what it meant for us and share a bit we are comfortable with, with other members of the group.

Task: We are all sometimes helped by others. And sometimes receiving help is harder than giving it. Yet, we all need help. Together in a group, find a way to encourage your Facebook support group member to share experiences of how they received helped (it can be something small or big) and what it meant to them.

Annex 14: Worksheet 14

Dear core group members! Year is approaching an end. And an end of the year is good to look back at what we have done, to celebrate and look forward to what we still want to do.

But as always let's first start by looking at how we are since we last met - has anything good happened, something that was good for both you and the person you provide care for? Has there been anything particularly difficult? Let's share one thought with others.

1. Today we'll take some time to look back at the work done during the previous year. Let's close our eyes and let's walk together through our time together, starting with the training in Ljubljana, continuing with the regular meetings throughout the year, making videos, taking about different topics, preparing posts...:
 - a. What did we gain by being part of this group? What did we learn?
 - b. If we would need to choose one good thing to carry with us from this group – what would it be?
 - c. Was there something that we would have done differently?

Let's keep silence for about 5 min and let us write our answers down – what we write down stays longer 😊 Than let's share our answers with a group starting with the oldest or youngest member of the group.

2. How do we plan to celebrate all that we've done during this year?

3. What are our plans for the future? For the next year? Will we continue our work? In what capacity will we meet? Where? How often? Will anything (any role) change?

4. Finally, let's do part of that also for our Facebook group members:
- a. How can we evaluate the work done during the previous year in our Facebook group? Some ideas: we can ask Facebook group members some questions OR together in a group we count the posts and reactions in our group and we post an information about the achievement...
 - b. How can we celebrate together? Some ideas: we share a special message, video...

5. Let's connect:
- a. In the following weeks don't forget to look up also Facebook support groups of other members. It can be a group activity. React to their posts and share the posts that can be actual to your group as well.
 - b. Let's also connect our Facebook support groups with the learning platform we developed. By sharing small segments of the learning materials with the link we can invite more carers to benefit also from the knowledge we gathered on the Resil4Care learning platform.

*Due to the length of this worksheet, it is advisable that it's content is divided into two or three meetings. There are many options how to go about it – you can combine question 1 with question 4a and question following by question 2, leaving questions 3, 4b and 5 for the second meeting or you can do something else – but final decision lies with each group leader. It is important to note though that all the ingredients are important: looking back, celebrating and looking forward to future work or closure. Since they have to be clearly stated to all members, I encourage you to do all the steps.