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EDEN

Community Collaboration Concept

Creating insights and Knowledge



The Project Partners in the Embracing Dementia project are:



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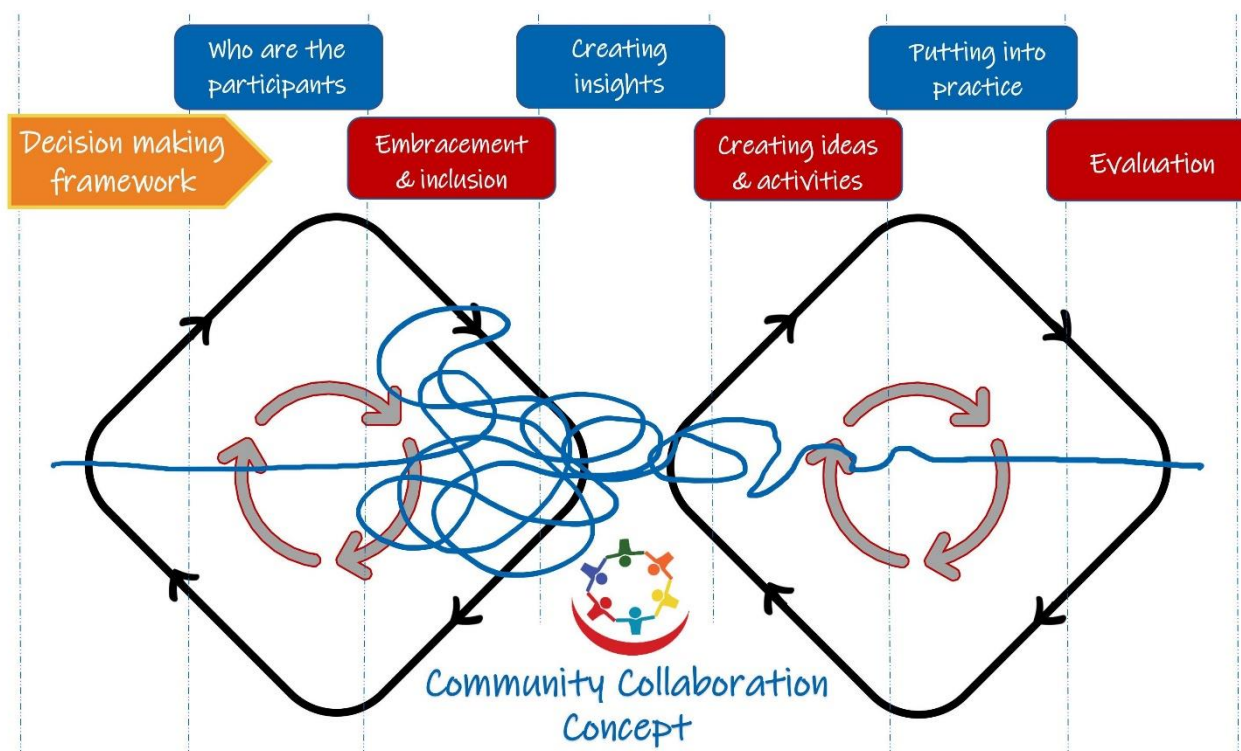
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3.2.1 Decision making Framework¹



This section has been included in the process model as it is usually regional or local politicians, policy makers and decision makers who are responsible for decision making and development of strategies that support the creation of communities that embrace dementia. Policy- and decisionmakers suggest and implement policies and strategies on how to use public resources within areas such as health and social care, or in terms of engagement with volunteers and civil society organisations.

The main objective in this section is to motivate and support the creation of an overall vision for active ageing and promotion of a community embracing dementia on the policy level (e.g. by politicians and decision makers). Politicians and local decision makers play a key role in putting forward plans which ensures that local communities are vibrant, inclusive and supportive of all citizens including PwD and their relatives. The aim of dementia plans, policies or strategies in this respect, are typically:

- the wellbeing of PwD, for instance removing stigma or providing better supporting structures
- to help the relatives and relieve stress on the family of the PwD, either by building the relevant health and social care and support,
- or by supporting non-for-profit organizations in order to make them ready to take part

For the sake of sustainability, it is important that policy and decision makers create a clear definition of which target groups they aim to reach and which policy areas or levels are involved in reaching the defined aims.

¹ Inspiration gained from the PoHeFa project



Supporting PwD and their relatives in living as a part of the community not only strengthens their quality of life but also reduces the economic costs.

Being a part of a local community, receiving informal support and acknowledgement is of great importance to both PwD, the relatives and to the society. When making strategies or policies, it is often relevant to provide research or methods, that makes the pathways in the strategies clearer to decision makers.

This could be done by identifying relevant knowledge from international or national research, or from local practitioners and volunteers, who can help point out what already works.

Building on existing knowledge can help decision makers to draw up the right match for the local area and their specific needs and wishes.

Without support from the local health authorities, there is a risk that the relatives cannot cope with the task of supporting and caring for the their family member with dementia, leading to a much higher need for assisted living facilities with the resulting human and economic costs for the family and the society.

This calls for the local health authorities to consider:

- A strong emphasis on structured support for relatives that enable them to cope with the task of helping their family members living with dementia - through supporting community collaboration.
- A shared language and a shared understanding of active ageing and what social inclusion and embracing dementia means, are needed because this provides a clear sense of purpose for all.

Political and administrative systems normally has three main political measures: 1) Regulation, 2) creation of incentives and 3) being informative. In the following, a few key examples are given below, on how these measures can be utilized when working strategically with including persons with dementia through dementia friendly communities.

Regulation includes making commands, having requirements and being prohibitive. The following examples seek to demonstrate regulative policies.

- Commanding e.g. the values and objectives of a municipality give organisations a specific direction, to make sure dementia inclusiveness is in focus – for instance by making policies, guidelines and communication about dementia, to show public focus on the issue.
- Requiring e.g. a club or society will receive funding by municipalities if they work with dementia - to make sure they have a strong focus on dementia
- Prohibiting e.g. banning specific activities that do not support their policy, e.g. which are not inclusive to PwD.

Creation of incentives includes grants, subsidies, special offers and alteration of specific areas/settings.

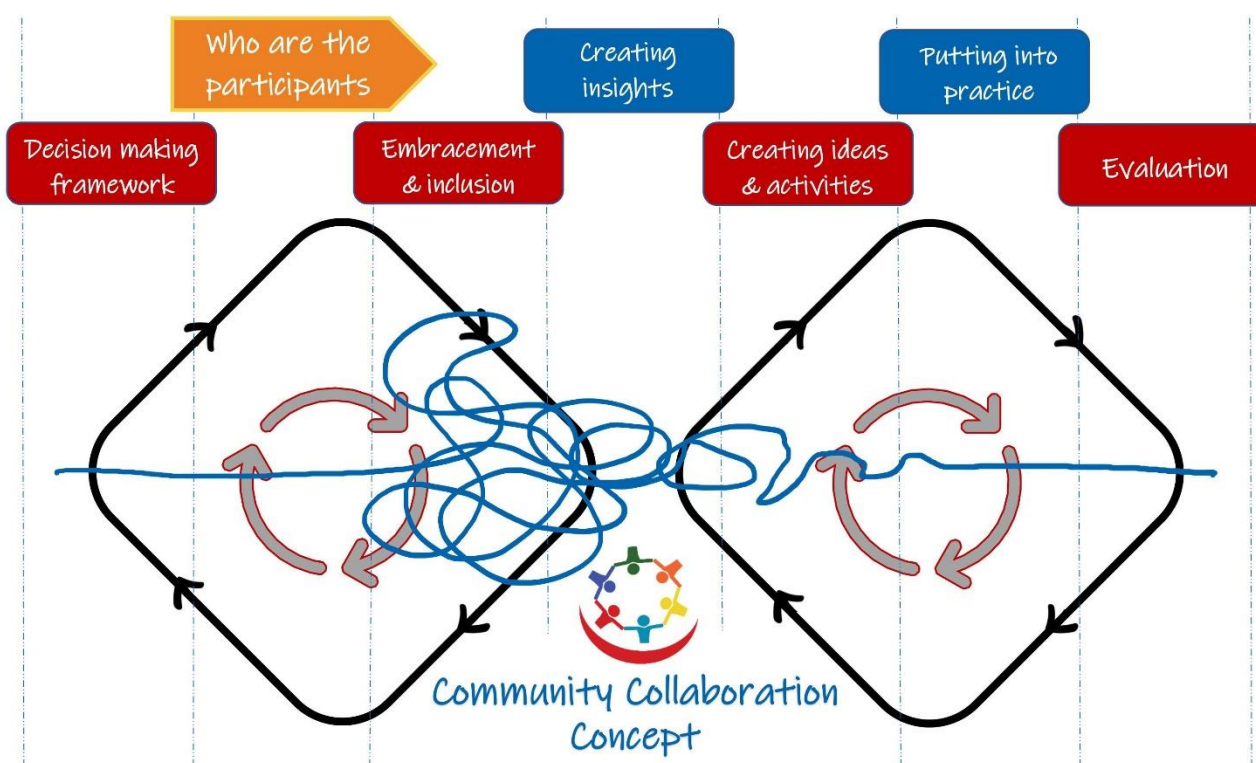
- Grants/subsidies e.g. grants to organizations, groups etc who initiate projects which promote inclusion of PwD.
- Subsidies: cheaper membership to voluntary organisations for citizens who take care of people living with dementia.
- Special offers e.g. activities organised by the local municipality for people living with dementia and the relatives / care givers – this could be done in public institutions like schools, libraries or museums



Information includes campaigns, advice giving, teaching, debate and dialogue.

- Campaigns and information: raising awareness about dementia, in order to remove stigmata and point out the societal challenges with regard to dementia (not just an individual challenge).
- Advice giving: how can neighbors, friends, shops and businesses etc. help persons living with dementia and their relatives. (There are several posters in the Community Collaboration Concept that can be used and adapted to specific local needs - chapter 6 with Tips and Tricks Posters)
- Building competences: education for health care professionals, volunteers and/or informal caregivers. If this is done in a coherent way, it helps all parties to have same 'point of view', and thereby strengthen the common knowledge base. This calls for the kind of coordination from the local, regional or national decision making bodies

3.2.2 Who are the participants and how can they participate?



In this section of the model, it is important to create an overview of the relevant local and maybe national stakeholders that should be involved in the process of creating a community that embraces dementia. The stakeholders can be different from community to community, but for the purpose of describing the community collaboration concept and the process model, a list of 6 categories have been identified, these are;

- 1) Health and Social Care Professionals.
- 2) Relatives.
- 3) People living with Dementia (PwD).



- 4) Social Society Organisations and NGOs.
- 5) Volunteers, common people and schools.
- 6) Local businesses.

Health and Social Care Professionals

The Needs Analysis that was carried through in the EDEN project, shows that HSCPs are very attentive and engaged in establishing tailored care and continuity in the relationship and collaboration with PwD and the relatives. For these professionals the major obstacle in their work is the lack of time and resources combined with the roles of the formal care systems.

An intensified community collaboration combined with shared knowledge about dementia and how to deal with dementia, will support the professionals in taking care of PwD and relatives. The professionals can contribute to the collaboration with knowledge about dementia combined with competences in supporting local collaboration and co-creation.

Relatives

In general, relatives adapt their life and everyday activities and devote their time to the assistance of the PwD. The majority of the relatives has to manage not only PwD's needs but also other competing needs. These included, for example, manage other family necessities (e.g. children's and other family members' needs), face the relationships with multiple formal and informal caregivers, and find time for own needs regarding health, work and social activities. Many participants admitted that they did not feel adequate, ready and trained for their role of caregiver, as well as they needed for personal support to accept the diagnosis of dementia and to manage the difficulties of their life.



The relatives call for more information about the disease and how to support their beloved one. Furthermore, the relatives lack recognition, acknowledgement and understanding and often feel rather excluded from their former friends and relations.

Community collaboration is a way of practising social inclusion and will acknowledge the efforts given by the relatives. The connection between the Community Collaboration Concept and the learning and teaching materials also supports the relative's knowledge about the diagnosis and how to deal with the role as a relative and caregiver.

People living with dementia

Despite of loss of cognitive abilities, PwD are still experts in their own life. They have, as everyone else, dreams and expectations for their life and knows what brings quality and meaning into their everyday living. They are in the early stages of the disease able to participate active in local community activities and thereby contribute to the society. Therefore all activities for PwD has to be performed with the person. As the disease progresses they might lose ability to contribute and to express their wishes and desires in verbal, but it is still important to include them and their interests in the collaboration and activities.



Civil Society Organisations and NGOs

CSOs are usually psychological and social support organizations structured on a voluntary basis and are most often only partially publicly funded aimed at supporting PwD and their relatives. The Needs Analysis shows that despite services offered by the CSOs varied and the connection with public system/health and social care providers were different among the countries, their main and common role was support and help families by replacing the lack of official health care system support.

The CSOs have the ability to create “bridges” between the professionals and the relatives, not obliged to delivering professional care and not burdened by politically or legal decided tasks. By offering support, the CSO’s also expresses understanding, compassion and acknowledges the relatives.

Volunteers, common people like neighbours and schools

Very often, the volunteers are engaged through the civil society organisations, that very often collaborates closely with local authorities in order to align the voluntary activities that is provided so that it supports and compliments in the best way, the official and publicly funded health- and social care and cure interventions.

But volunteers can also be seen as common people like neighbours, colleagues and friends, as they can support and make the understanding of embracing dementia real, by doing little things in the daily life such as showing compassion, empathy and understanding, and by listening and visiting the homes where dementia is a part of daily life.

Young people and schools can also become a resource. Since 2012, when the “European Year for Active Ageing and Solidarity between Generations”, was implemented, this theme has been high on the European political agenda, and member states and communities are encouraged to explore opportunities where generations meet activities, where generations support each other with their different resources to create win-win situations.

If you want to know more about good practices and stories in this field, we invite you to visit the AGE Platform Europe News section: <https://www.age-platform.eu/good-practices/intergenerational-solidarity>

In the tips and tricks section in chapter 6, posters are available which can be used to raise awareness on how neighbours and citizens can participate to assist PwD in their daily life.

Local Businesses

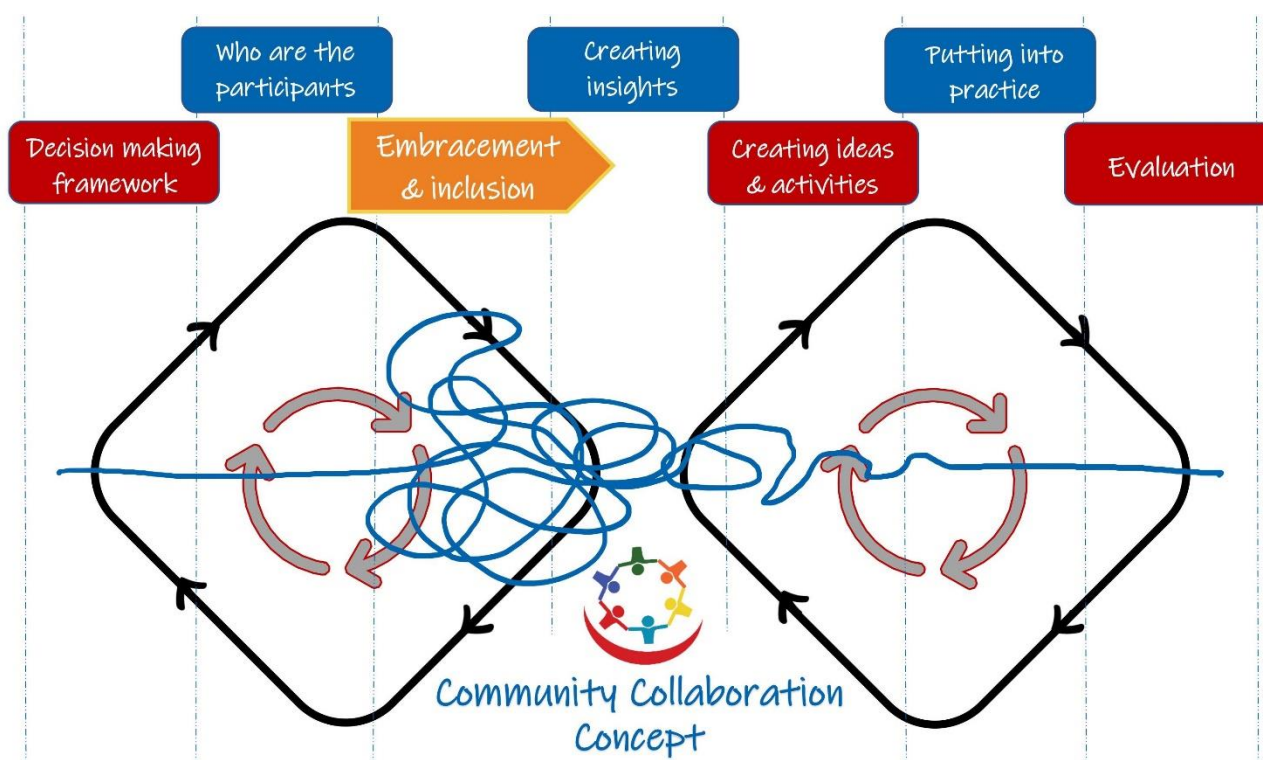
Collaboration with local businesses should be constructed with a win-win approach; by giving something to the local community, a local business should gain something else.

PwD and their relatives are consumers like all other citizens, but with special needs in relation to the fact that dementia is a very important part of their lives. Local businesses can therefore participate in creation local communities that embraces dementia, by e.g. sponsor ships to create physical environments that makes it easy for PwD and their relatives to participate in social and community activities. On the other hand, the local business can design physical and / or online structures which makes their business “dementia friendly”, which the local community is engaged to use and promote towards PwD and their relatives.



In the tips and tricks section in chapter 6, a lot of posters that can be used to raise awareness towards the different stakeholder that have been mentioned here, are available for download and adaption to the specific local community that wants to work with the Community Collaboration Concept.

3.2.3 Embracing dementia and inclusion



Embracing dementia is an important part of the active ageing debate and political agenda in Europe, and active ageing is - according to the World Health Organisation (WHO) - the process of optimising opportunities for health, participation and security in order to enhance quality of life as people age. Active ageing allows people to realise their potential for physical, social, and mental well-being throughout the life course and to participate in society, while providing them with adequate protection, security and care when they need it. In addition, the WHO underlines that interdependence with other people (family, neighbours, work associates and friends) and intergenerational solidarity are important tenets of active ageing.

Following this definition, the idea of this section of the community process model, is to create a shared understanding of how to understand some of the most important aspects of what makes a community that embraces dementia, insuring that PwD and their relatives can stay included in the community and continue living an active life as long as possible.

In order to ensure that all participants are working for the same objective, it is important to make sure that the participants all have the same understanding of areas such as;

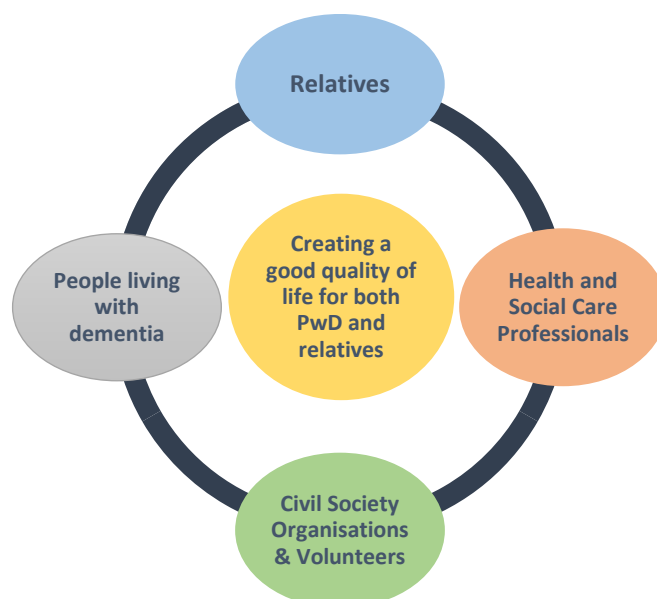
- How do we understand a good quality of life for both PwD and relatives?
- How do we understand active ageing?
- How do we understand embracing of dementia?



- How do we understand dementia? Is there a specific age group that we want to deal with and how should we deal with different stages of dementia?
- How do we understand inclusion and which target groups is it that we want to include?
- How do we understand collaboration?
- How do we understand intergenerational solidarity?

In the need analysis it was made clear that especially 4 themes are important for PwD and their relatives, and these 4 themes could be put forward as the overall success criteria for the implementation of the Community Collaboration Concept.

- 1) PwD and relatives should be empowered to be able to cope with the future.
- 2) PwD and relatives should feel supported and have easy access to collaborate with others.
- 3) PwD and relatives should have access to networks and activities that help them become or stay socially included.
- 4) The understanding of dementia in the local community should be built on principles of empowerment, acknowledgement and flexibility in relation to the different stages of dementia, life situations and family cultures.



It will be useful to describe your own local vision for what a community embracing dementia means for the relevant stakeholders and participants. An example of a local vision could for example look like this.

Example of a local vision and shared understanding of a community embracing dementia

<https://www.luoghicura.it/servizi/domiciliarita/2020/01/la-comunita-amica-delle-persone-con-demenza-un-progetto-di-rigenerazione-umana-a-giovinazzo/>

<https://www.casaemmausts.it/diurno-progetto-cuoche>



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The activities and tools which are mentioned in the section about co-creation and design thinking, can be used to create workshops, where the stakeholders work, discuss and explore together, in order to reach a shared understanding.

Relevant links and inspiration

If you want to find inspiration on how to create workshops on shared understanding, we invite you to visit the following websites;

In English

In Danish

In Dutch

In Italian

<https://www.osservatoriomalattiaare.it/alzheimer/14955-demenza-la-rete-italiana-delle-comunita-amiche-per-l-inclusione-dei-pazienti>

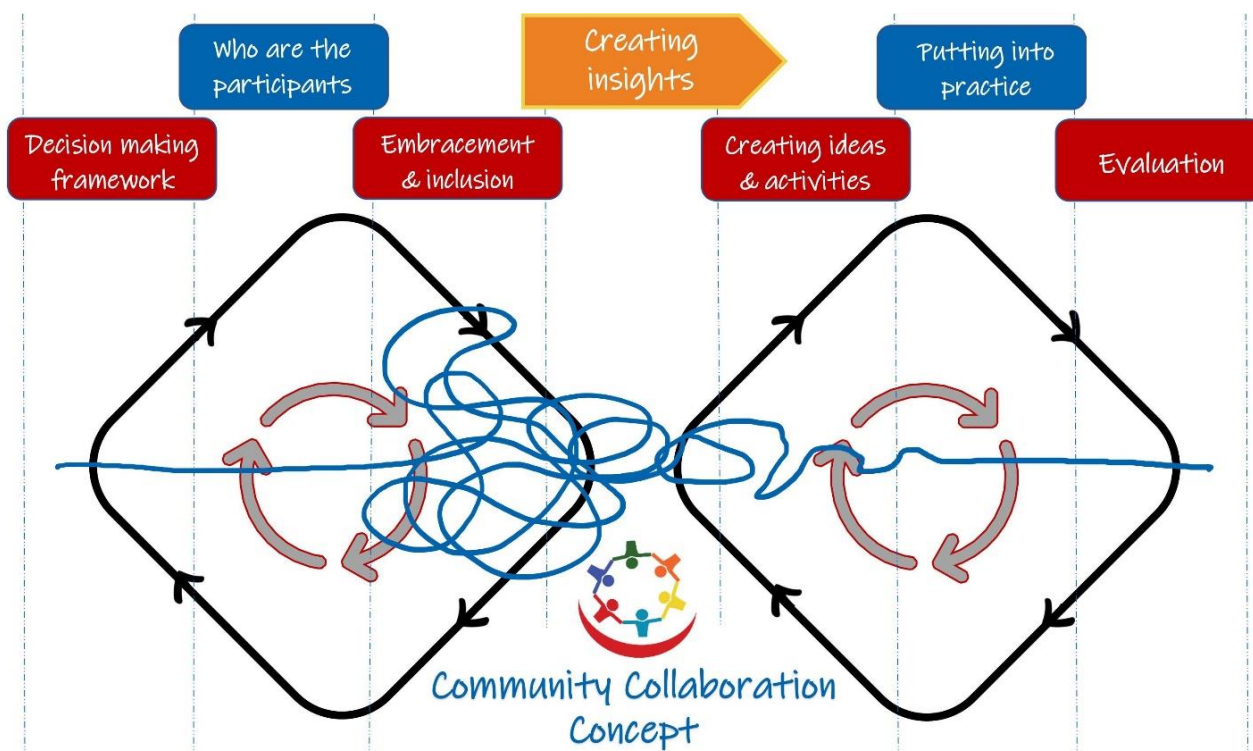
<https://novilunio.net/diritti-partecipazione-e-inclusione-alla-conferenza-di-alzheimer-europe/>

<https://www.luoghicura.it/servizi/domiciliarita/2020/01/la-comunita-amica-delle-persone-con-demenza-un-progetto-di-rigenerazione-umana-a-giovinazzo/>

In Spanish



3.2.4 Creating Insights



A very well-known challenge within innovation, is that solutions to the challenges are often found before the challenge has been thoroughly explored and identified.

Starting by finding answers and solutions to the overall societal challenge, in this case how to create a community that embraces dementia, creates a big risk that it is a really good answer. But perhaps to the wrong challenge, because a lot of missing sub challenges and context specific factors have not been explored.

It is therefore very important to create sufficient insight to view the problem from several angles, ideally from the side of all stakeholders. In this section the idea is to get to know enough about the group of people who should benefit from the changes, and ask open questions that can provide the right insight to the process.

In the following, a “communication tool” is presented that can be used to create insights and to set up and facilitate a dialogue between the PwD, relatives, volunteers and HSCPs about what REALLY matters in relation to dementia. To get a deeper understanding about the fact that this disease influences the society and its citizens in an increasing way.

The “communication tool” can be used to enhance collaboration and help focus the attention on what is important in the life of the person living with dementia. To find out if there are any wishes, needs or just things that make them happy. What can be done to give this person more control and a higher level of happiness and wellbeing.

This conversation can take place in their own home or any other place where they feel comfortable.



Based on Positive Health principles, the suggested steps and questions are aimed at finding possibilities instead of problems so the person living with dementia and their relatives get the best possible support and quality of life.

- Firstly, it is important to look at the daily life and structure of the PwD: What is going on and how does the current situation look like?
- Secondly, the focus is on the PwD: What is important to him/her and are there any specific needs or wishes?
- After this, as a third aspect, focus is turned to the relative/caregiver: Are there things he/she find difficult? What do he/she enjoy to do?



Daily life and structure

How does the day look like?

What support do I have
(or do I need)?

Who are important
to me?

My day

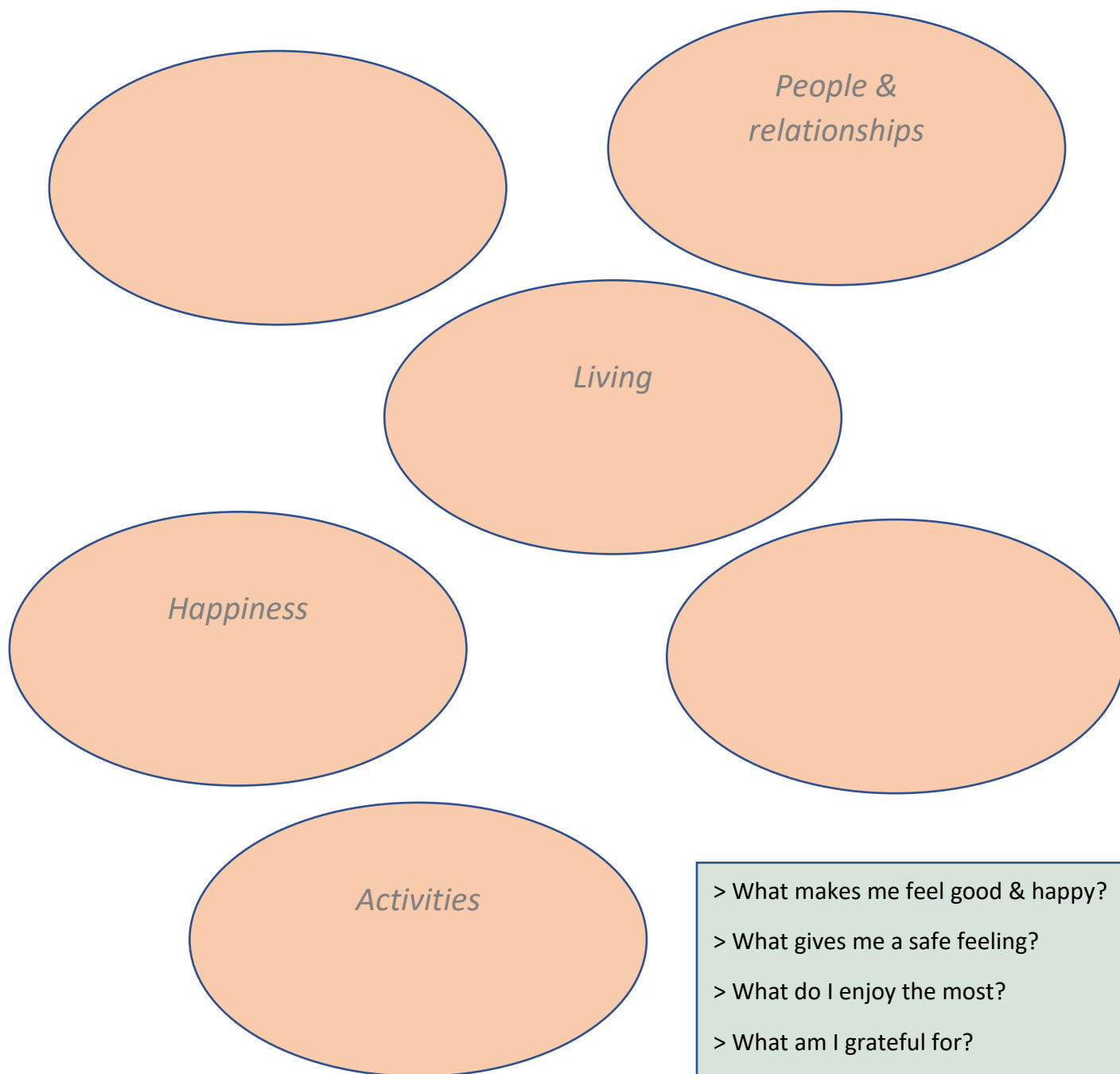
What are important
(daily) activities?

What facilities do I need and
are nearby?



What is important to me?

My wishes and needs



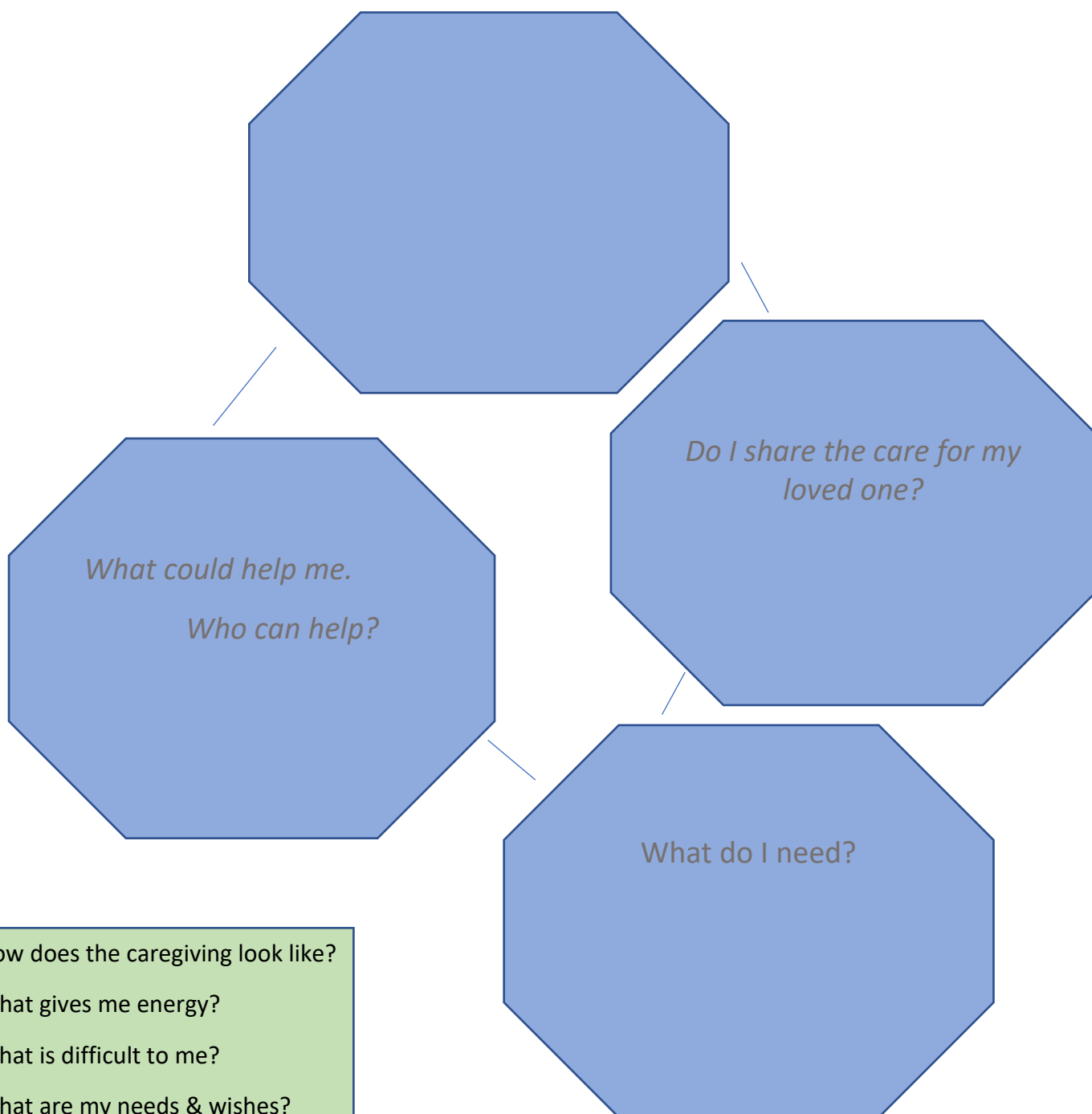
- > What makes me feel good & happy?
- > What gives me a safe feeling?
- > What do I enjoy the most?
- > What am I grateful for?
- > What do I like to do the most?
- > Do I have any wishes – big or small – that I would like to see come true?

Focus on the person with dementia



Who is giving care?

What care do I provide and what are my needs?

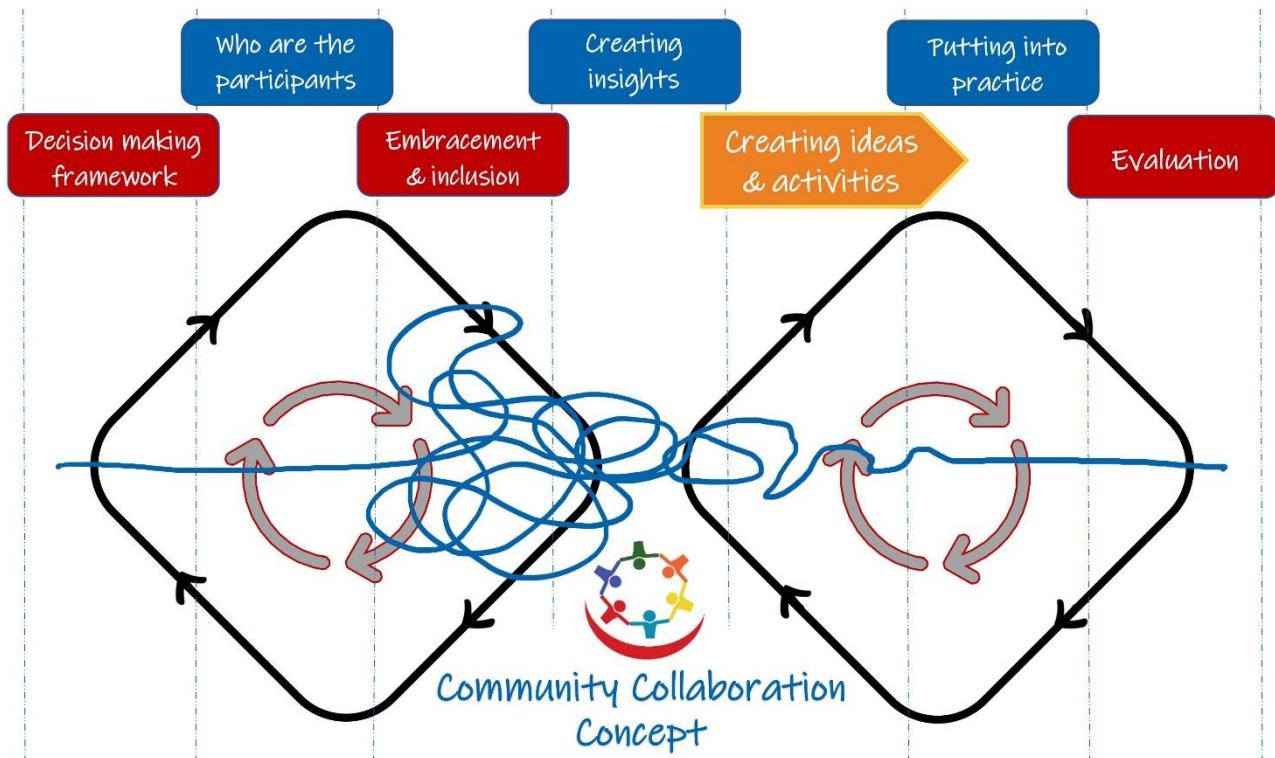


- > How does the caregiving look like?
- > What gives me energy?
- > What is difficult to me?
- > What are my needs & wishes?
- > What do I like to do for myself?

Focus on the relative



3.2.5 Creating Ideas and Activities



When creating ideas and activities, it is important to take the starting point in the insights that were gathered in the section just before. Based on the challenges and possibilities that were described in the 'creating insights' section, this part is devoted to co-create ideas and activities together with the relevant participants.

It is highly recommended to use co-creation approaches, and these were explained in section 3.1.3, so in the following, only the overall benefits of co-creation is summarised.

Key-points of co-creation

- End-users; seek and value their experience.
- Mutual development of solutions / identification of problems.
- Based on Participatory Action Research (PAR) methods.
- Appears to be messy but it is a process.
- Central to solution development.
- Applicable to product, service, organisation, urban design... etc.

Aims of co-creation

- Gather people with a shared goal.
- Share different approaches product development and services.
- Explore new ways of working within existing constraints.



- User-centred; seen through the user's eyes.
- All end-users are involved in creative activities.
- Create physical artefacts to represent ideas.
- A process, not a snap-shot of user experience.

Advantages of participating in co-creation

- Experience makes users, the 'expert'.
- Inclusive – all users participate and have their say.
- Empowering.
- Relaxed, informal environment with playful atmosphere.
- Better understanding of other's problems and solutions (as well as one's own).
- Efficient process.

Outcomes of co-creation

- Better understanding of user needs, leads to successful result.
- Development of a product/service that users truly want.
- Empathy for user relationship with products, services.
- Persuasive - data gives powerful words and pictures.
- Allows innovation in the right direction.
- Avoids taking too many wrong turns.

There are many different kinds of workshops that can be organised to create ideas together, and if you want to find inspiration to organise workshops, we invite you to visit these websites;

www.ccw-project.eu

Xxxxxx

Xxxxxx Do we any links to put here? Or else delete

You can use the following 1 activity card to formulate the ideas which are developed in the co-creation process as well as to formulate an implementation plan.



What are the possibilities?

Creating Ideas Together

Ideas to Implement

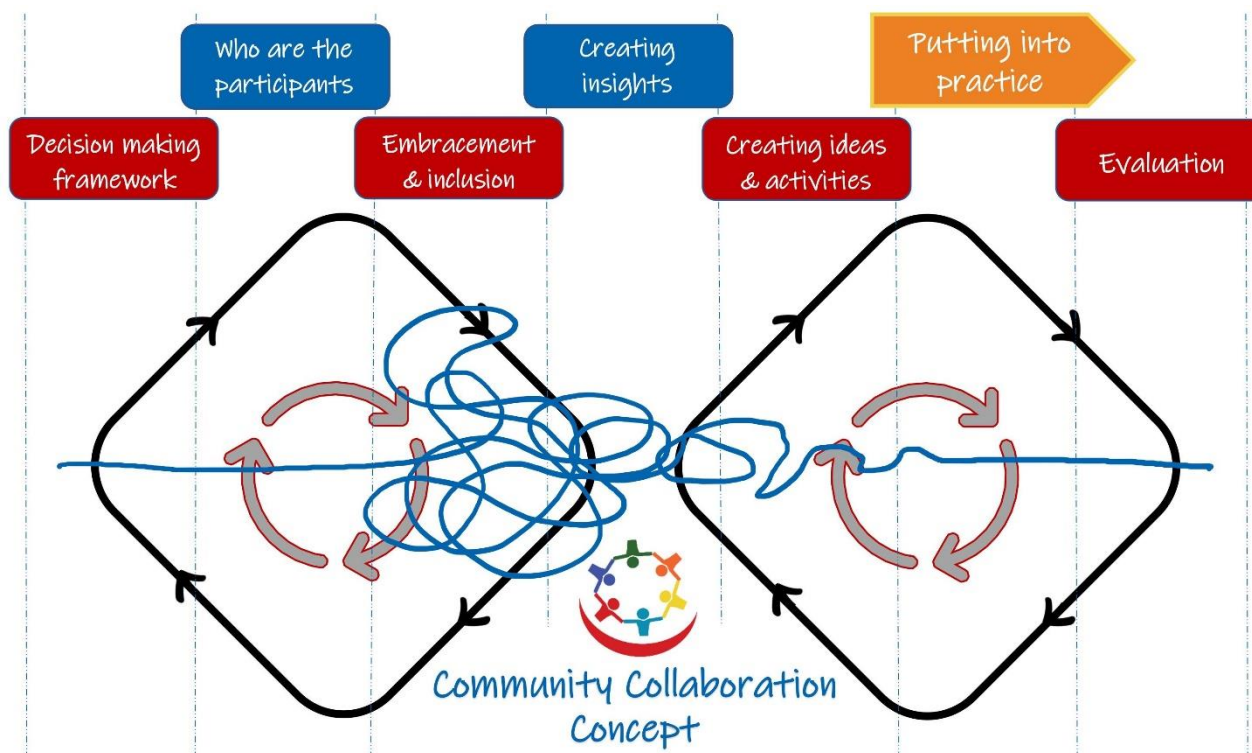
- Which wishes & needs are the most important?
- What gives the most energy?
- What is difficult?
- What does the caregiver need?
- How can we change things more according to the wishes and achieve this together?

What are we going for?

Actions!



3.2.6 Putting into Practice



Defining a concise and effective implementation plan is important to bring clarity to the overall vision and determine the purpose and goals of the different activities that you have decided to implement within the co-creation process.

Action planning has several specific advantages:

- It helps you to bring structure and organization to your ideas and thoughts.
- It helps you to identify the steps you need to take to pursue your vision.
- It helps you to keep track of who will take action on what by when.
- It helps you to understand how you are going to carry out the intervention(s).
- It helps you to plan collaboration with other actors
- It helps you to take the right action step at the right time in order to implement the intervention in the best possible way.

In this step, the ideas and activities that were developed and planned in the former steps, are put into action. An activity is carried out, a process is started, success criteria and relevant indicators are listed, target groups are involved actively, learning is created and follow up plans are developed and executed.

It is beneficial that activities and interventions are implemented within an action learning approach, so that you create the best opportunities to learn from your work.

- It helps you to get a new repertoire.
- It helps you to be flexible during activities - form and content can be changed if needed.
- It helps you to let the participants have a say.
- It helps you to be learning by doing.

Powerful questions

Active listening

Sharing and learning

Reflection

Action

Group and individual development

Action Learning



What are the possibilities?

Activity Card

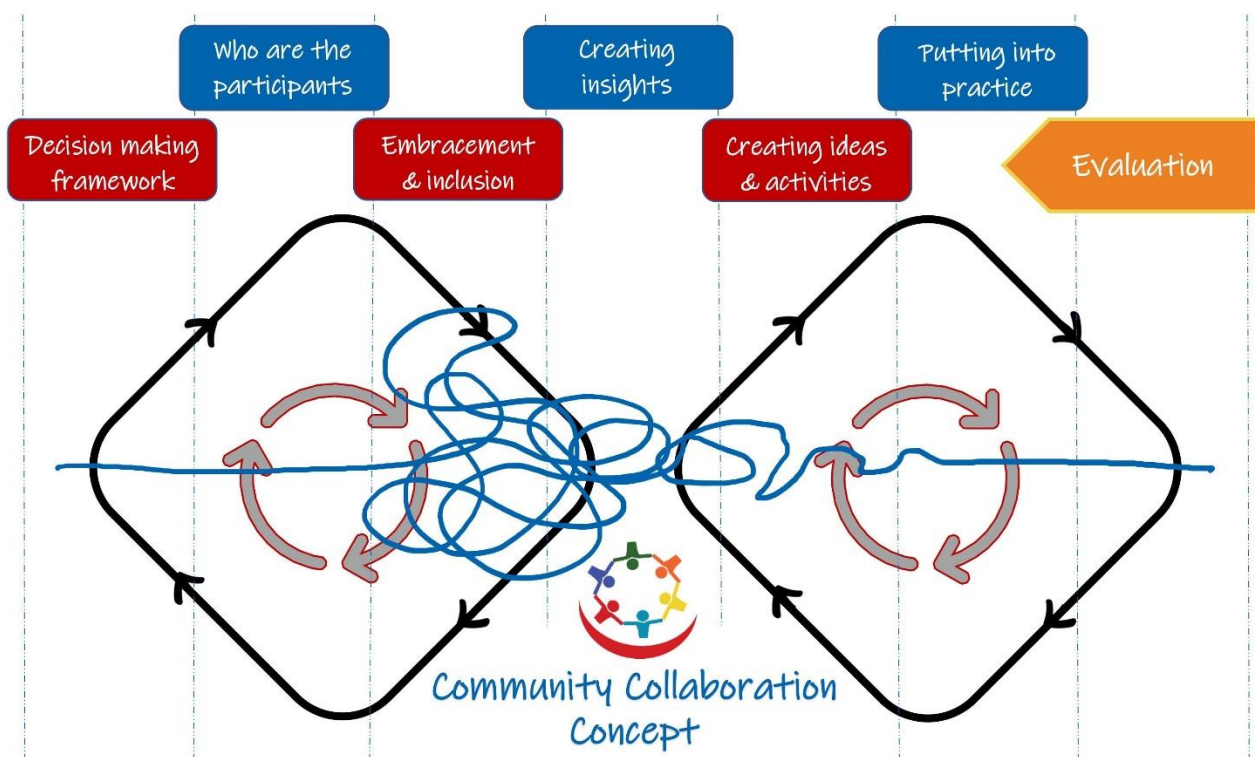
Implementing Ideas

- What are we going to do from now on?
- Who's going to do what?
- When will we do things?
- When will we evaluate?

What to do and who is doing what?
Actions!



3.2.7 Evaluation



As part of the co-creation process, stakeholders should, in collaboration, set up a number of concrete success factors and indicators. These need to be based on local and specific conditions, cultures, structures, projects etc. and it is therefore not relevant to list a general list of indicators here.

But it is relevant to base the evaluation and the development of indicators on the four main needs that came out of the needs analysis, as these are the ones that have been the basis for the development of the community collaboration concept, and the gathering of learning material that is available from the embracing dementia platform. These main themes are;

- Theme 1: How to be able to cope with the future.
So an indicator overall could be: Does the use of the community collaboration concept help to implement activities that makes it easier for the PwD and their relatives to cope with the future?
- Theme 2: How to feel supported and collaborate with others.
So an indicator overall could be: Does the use of the community collaboration concept help to implement activities that makes it easier for the PwD and their relatives to feel supported and collaborate with others?
- Theme 3: How to become or stay socially included.
So an overall indicator could be: Does the use of the community collaboration concept help to implement activities that makes it easier for the PwD and their relatives to become or stay socially included?



- Theme 4: How to understand and cope with dementia.

So an overall indicator could be: Does the use of the material on the community collaboration concept help to implement activities that makes it easier for the PwD and their relatives to understand and cope with dementia?

Evaluating the processes and results of an activity is essential to find out how the activity was received by the target group, to see if it had any (short-term) effects, and to determine whether it could be improved in any way. In other words, evaluation matters to your project for the following reasons:

- It helps you to assess if your project is achieving its goals.
- It helps you to enhance future initiatives with lessons learned.
- Evaluation criteria should be defined prior to the implementation so that a continuous evaluation is possible.

Using the following evaluation framework can be helpful to plan and carry through the evaluation activities. The framework includes the 4 basic themes from the needs analysis, which can be used to plan the evaluation on a general level, and it is also possible to include more local and individual indicators for the specific community.



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Evaluation Framework

Community Collaboration Concept

Expressed Needs from the target group in the EDEN project	Success criteria and goal description	Concrete activities and interventions	Concrete Results and outcomes	Evaluation questions (what)	Evaluation method (how)
Overall Embracing Dementia Needs					
How to be able to cope with the future.	What is the desired goal for each need and can you put up a measurable success criteria.	Within the CCC, what did you decide to develop as activities and interventions to respond to the expressed needs	What were the concrete results that came out of the Community Collaboration?	Decide which questions you would like to ask the stakeholders to explore how they experience the activities and results that have been produced during the community collaboration	Decide how you want to gather answers to the evaluation questions. Should it be questionnaires, focus group interviews, one to one interviews.
How to feel supported and collaborate with others.	The goal could be formulated as; we want the PwD and their relatives to have easy access to support, which makes it easy for them to cope with the future.				
How to become or stay socially included.					



	A success criteria could e.g. be expressed as a percentage for the number of PwD and their relatives who should have positive experience with the individual needs.				
How to understand and cope with dementia.					
Individual Community Needs					
Mention any specific needs that you have elaborated on community level	Success criteria and goal description	Concrete activities and interventions	Concrete Results and outcomes	Evaluation questions (what)	Evaluation method (how)



3.3 Training into the use of the community collaboration concept and co-creation²

Working with the Community Collaboration Concept, with all its aspects of using methods like co-creation, design approaches, fostering empowerment among the citizens and the local communities, calls for a new approach of preparing and training the professional practitioners working within health and social care.

In order to prepare and manage local co-creation processes, professional practitioners will need to learn how to become multidisciplinary process facilitators instead of “just” being a civil servant doing “case working” based on clear guidelines.

Professional practitioners will need to learn something about the ability to a) lose control, giving room to other opinions and solutions, b) creating a holistic view, looking for diversified opportunities, c) have more focus on the process and not only on the product, d) create conditions for improving empowerment among stakeholders, and e) use their professionalism and their professional identity to establish co-creation processes, because co-creation does not at all mean, that we do no longer need the professional practitioners, they just need to apply their professional knowledge in another way.

The CCW training course material is constructed with four overall training themes, which will take the attendee through the entire process of initiating, facilitating and evaluating an entire co-creating process.

The four training themes / course days are the following; 1) Creating a common understanding of co-creation, 2) Initiating the co-creation process through collaborative problem formulation and evaluation, 3) Managing the co-creation process and 4) Dissemination and communication of the co-creation process and its results.

If you want to know more about the co-creating welfare project and eventually use the training material, which consists of a substantial package of co-creation activities that can be used in concrete co-creation processes, you can visit the project website on www.ccw-project.eu

² Inspiration gained from the Co-Creating Welfare project



1. UNDERSTANDING AND EMBRACING DEMENTIA

The world of a PwD is not the same world in which their families, friends and caregivers live. Their reality varies from day to day, depending on the progression of the disease.

For some PwD, their reality may include deceased friends, parents or other loved ones. Another person might be living in an era where their spouse worked all day while they were responsible for maintaining the household and caring for their young children.

In the EU, many PwD live at home, where a high level of informal care is often given by their partners and/or their adult children. Many caregivers invest a lot of their leisure time, self-care and sustain health expenses. Meanwhile, some young caregivers' performances at work or school decreases or they have to leave work altogether to care for their family member. Relatives grieve the loss of their loved one, the person they were and their dreams of what this time in their life would be like.

Caring for those living with dementia is challenging. But challenging as it may be, stigma and discrimination make it even harder. There is a need to raise public awareness, improve understanding of dementia and how to deal with it.

Embracing dementia means that you not only accept where a PwD is in their dementia related world, but that you join them in it. Embrace them as the person they are, with all the abilities, feelings, thoughts and memories that still remain.

By engaging communities and helping each other we create a dementia-friendly environment where relatives will be more supported with the coping and accepting of their new lives. They can begin "to not just survive, but to thrive".

Step into this world in which PwD can be who they are becoming while their relatives feel accepted and supported. Dementia takes away so much, do not allow it to steal the person's sense of self!

Interacting with someone who has dementia can at times be challenging or confusing. Dementia will gradually affect the way a person communicates and the person you know and love may behave differently than before the diagnosis of dementia.

As the dementia of Alzheimer's progresses, you will notice changes in communications and behaviour. The ability to present rational ideas and to reason clearly will change. There is also trouble finding words, increased hand gestures, easy confusion, even inappropriate outbursts are normal and can occur.

Remember that a PwD is trying to make sense of a world that seems to have gone seriously off-track for them. Even ordinary, daily tasks may have become challenging.

While you may want to avoid conversations that might be stressful, it's important to continue interacting in a way that honours who they are as a person.

Sometimes we do not realize what we say or how we say things. This can trigger distressed behaviour, making it even more difficult to give quality care to a PwD.

Whether you are interacting with PwD as a nurse, a general practitioner, a social worker, a caregiver or a random family member or neighbour, it is always very important to treat this person with respect, patience and understanding.

**"The way we communicate with others and with ourselves
ultimately determines the quality of our lives."**

author Tony Robbins



So how do we communicate and interact with someone who has dementia? What is the best approach for them and what should you not do?

The main goal is to keep a calm atmosphere and give the PwD the chance to think independently without overwhelming them with demands. Going along with their mindset is much less agitating for this person than contradicting what they are saying, so: join their journey!

The following pages will give you more information about this and show you tips on how to interact with a person living with dementia in a positive way and with a dementia-friendly mindset.

4.1 Embracing dementia

Dementia can affect the way that someone thinks, feels and behaves which can significantly impact the way they operate within and relate to their local community. Some common symptoms include: progressive and frequent memory loss, disorientation with time and place, apathy and withdrawal or problems with communication. However, each individual's experience of dementia is unique and that is why a person-centred approach is so important.

A community that embraces dementia starts close to home and you too can contribute to this! Together we can create a safe, pleasant living environment for PwD and their loved ones. An environment where dementia is recognized and acknowledged, where the disease is openly discussed and where people know what to do in certain situations. That way PwD are not on the sidelines, but they can continue to actively participate for as long as possible.

Everyone can help make their community more dementia-inclusive. From family to friend(s), from supermarket to pharmacy, from book club to bus driver, from sports club to choir. Keep in mind that any change, no matter how small, can make a significant difference in the life of someone living with dementia and their relatives.

It is therefore important that bystanders know how to help in certain situations. However, not everyone knows how.

The next section of the Community Collaboration Concept will provide some knowledge and tips on how to react and what you can do.

In short, embracing dementia means:

- ❖ You can recognize someone with dementia.
- ❖ You know how you can help someone with dementia.
- ❖ You have an eye for what people with dementia still can do.
- ❖ You talk openly about dementia.
- ❖ You reach out and offer our understanding and support.



The following illustration shows possible points to recognise if a person shows signs of dementia.

Possible signs of dementia



**If you are experiencing any of these symptoms,
or know someone who is, talk to a doctor.**



4.2 What to do when suspecting dementia

Are you dealing with someone who you suspect is suffering from dementia? For example, you see someone walking or standing in the streets who is looking disturbed or anxious.

You can talk to that person as you go through the following steps: comfort, make eye contact and think along.

❖ **Comfort**

Talk calmly, introduce yourself and say what you are going to do. Join the conversation and do not contradict the other person. Be encouraging in the contact. Try to create a safe situation for the PwD and let him or her keep control as much as possible.

❖ **Make eye contact**

Make eye contact to check if you are understood and give the PwD time to respond. Try to summarize the situation by telling what you think is going on, use short sentences and ask simple questions. Try not to ask questions about the recent past and always see if you are understood.

❖ **Think along**

Ask the PwD if you can help. Sympathize with the ideas and wishes of the other and involve him or her in the solution. What would be a good next step to take and how can you best do this. Help him or her go in the right direction and state what you are going to do.

❖ **Thank you!**

Close the conversation in a good way. Thank you for helping someone with dementia. This way you also help to make your community more dementia-friendly!

4.3 Tips on how to interact with a person living with dementia

- **Make sure you have the other person's attention**

Gain the person's attention before you start speaking with him or her. Call them by name and tell who you are. Make eye contact. Eye contact provides a nonverbal cue that you are there for them, listening, and acknowledging their thoughts and feelings. Make sure that you are at the same height. So do not stand while the other person is sitting, but sit down too.

- **Use simple words and short sentences**

Use concrete, clear language and words that are familiar. Be sure to speak slowly, using a relaxed and reassuring tone of voice. Try to avoid a high and loud voice. Don't ask too many questions. Keep it to minimal choices ("would you like coffee or tea?"). Ask one question at a time and wait for the answer.



- **Be patient and a good listener**

Patience is key. Calmly wait for a response as the person may struggle for words. It's okay to suggest a word if this can help them but don't rush them. Remember, PwD need a little extra time. If you don't understand what they are trying to say, think about the emotion or intent that may be behind the words they're using. Respond with warmth, understanding and confirmation.

- **Speak to the person as the adult they are**

Don't speak or talk down to the person as though they are a child. People with dementia are adults and deserve to be treated as adults, regardless of the stage of dementia they are in. Setting a childish voice or getting too close, can be humiliating and intimidating. It can cause angry reactions and it indicates a lack of respect.

- **Talking with, not about**

Talk with, not about, the PwD. Assume that they understand what the conversation is about and don't ignore them. While they may not be able to do or recall everything like they used to, it's important to include them in conversations about their life and wellbeing. Never talk about someone with dementia as if they aren't there. Treat them with the dignity and respect they deserve.

- **Speak positively**

Accept that not everything has to be right in a conversation and don't be too strict on facts. The PwD may not know everything exactly anymore, but that doesn't matter. It makes little sense to constantly correct or disagree with them, instead you can give them a few compliments or an extra hug. Facial expressions are important too so do smile, but not in a mocking way.

- **Testing**

Don't test them with 'do you remember?' questions. Questions like: Do you remember my name? What day is today? What did you have for lunch? can lead to stress. People with dementia often have an easier time remembering the distant past than something that happened that day. While they may enjoy talking about memories from their younger years, don't ask about details or specific moments.

- **Maintaining independence**

Help the PwD to remain as independent as possible. It may be quicker or easier to do things yourself, but it is better for the person to do this for himself or herself. Allow them to continue practicing their daily activities as long as they are able to.

- **Break tasks into simple steps**

Divide an activity into parts and avoid complicating tasks by presenting clear and simple steps to follow. Do things together, step by step and show the actions. Give the other person time to copy it and give compliments if things go well. Don't give instructions or information too far in advance.

- **Avoid noisy places and distracting environments**

When the PwD is already struggling to recall words or understand what you are saying, background noise can create a distraction that discourages conversation. Simple changes to the environment and limitation of background noise can improve and enhance communication.

- **Guide and distract**

If the PwD becomes irritated, angry or impatient, let go of the goal you had in mind and focus on what the other person feels. Confirm that feeling, show understanding and try to distract by talking about something else or going for a walk together.



- **Embrace acceptance**

If you're living with or caring for someone who has dementia, embrace acceptance and don't get mad. Don't get caught up in discussions and use distraction to shift attention. Understand dementia is a progressive disease, and abilities and memory can change daily. Although it can be hard, it's important not to get stressed or annoyed with them when they have difficulty with a memory or activity.

- **Other forms of communication**

Communication does not always have to be a conversation. Singing a song together, watching photos, gently massaging hands or just sitting quietly next to each other are also ways of communicating and making contact.

- **Focus on possibilities**

Do not focus on what people no longer can do, but look at what they still can do and adjust your activities accordingly. Give compliments if things succeed and go well, how small they might be.

- **Enjoy the unexpected**

A conversation can sometimes take a surprising turn due to an unexpectedly funny remark or a spontaneous gesture. Try to go along with the situation that the PwD outlines and enjoy it together. Humour is a great tool in this and can add to the happiness of the both of you.

- **The good old days**

It cannot be said often enough, but use things from the past of the PwD. PwD almost always know and remember things from the past and if you talk about these, they will join the conversation. They feel confident and trusted which makes a positive and pleasant conversation. The short-term memory may no longer work, the long-term often does.

**With every choice you make when interacting with someone with dementia,
try to figure out how you would feel if you were treated that way.**

Respect is the magic word!



Don'ts

- ❖ **Don't** disagree, argue or correct. Don't engage in arguments
- ❖ **Don't** ask questions that rely on a person's memory
- ❖ **Don't** use negative body language and facial expressions
- ❖ **Don't** use a childish approach
- ❖ **Don't** assume the person with dementia doesn't understand
- ❖ **Don't** have a conversation in a noisy place
- ❖ **Don't** focus on impossibilities
- ❖ **Don't** talk 'around' or ignore the person with dementia
- ❖ **Don't** assume that every person with dementia is the same
- ❖ **Don't** invade their space, but also **don't** be afraid of touch
- ❖ **Don't** take things personally



Forget dementia, remember the person



Do's

- ❖ **Do** use simple words and short sentences
- ❖ **Do** allow plenty of time for a response
- ❖ **Do** listen carefully and make eye contact
- ❖ **Do** talk at eye level
- ❖ **Do** be patient, flexible, cheerful and reassuring
- ❖ **Do** include the person in the conversation
- ❖ **Do** treat the person as the adult he or she is
- ❖ **Do** be sensitive to the environment
- ❖ **Do** focus on possibilities
- ❖ **Do** provide encouragement
- ❖ **Do** use distraction as a tool
- ❖ **Do** learn about the person's past
- ❖ **Do** respond to the person's feelings rather than the words



Forget dementia, remember the person



4.4 Challenging changes in behaviour

In the middle to later stages of most types of dementia, a person may start to behave differently. For the person with the condition and those around them, this can be one of the most difficult aspect of living with dementia.

Sometimes these behavioural changes can be a result of frustration with not being understood or feeling they are not in control. In other cases it can be the fear of losing who they are or no longer recognizing their environment that was familiar to them for so long. All these feelings can affect behaviour.

If you're caring for or dealing with someone who's showing changes in behaviour, it's important to try to understand why they are behaving like this, which isn't always easy. You may find it helpful to remember that these behaviours may be a way of trying to communicate how they are feeling.

Some common changes in behaviour include: repeating the same question or activity over and over again, hiding and hoarding things, restlessness and agitation, disturbance in sleep, trailing and following a partner or caregiver, shouting and screaming and loss of inhibition.

Common changes in behaviour

The behavioural changes mentioned above are explained in more detail below with a few tips on how to deal with the specific behaviour.

- Repetitive behaviour

Repeating the same question or activity may be a result of memory loss where the person can't remember what they've said or done, or the answer they received to a question. They can also be repeating themselves because they feel anxious or frightened, and want comfort, security and reassurance.

- ❖ This behaviour can be very frustrating for the carer, but it's important to remember that the person isn't being difficult on purpose. Try to be patient and sensitive and find out if there may be a reason for the repetitive question or behaviour.

- Hiding, hoarding and losing things

Spending time trying to find things or make the person remember or tell where they put it, can be very frustrating. Hiding and hoarding may be an attempt by the person to have some control of their situation or is to hide or protect things because of fear that their things will be stolen.

- ❖ Consider some kind of box where the person with dementia can put things they want to keep safe. Don't leave important documents or items lying around. Check their 'hiding places' regularly.



- **Agitation and restlessness**

People with dementia often develop restless behaviours, such as pacing up and down, wandering out of the home and agitated fidgeting. Agitation can be difficult because it can take many forms and be very tiring.

- ❖ Check that the person has no pain or discomfort and make sure the person has plenty to eat and drink and that there is nothing in their environment making them feel uneasy. Having a daily routine and engaging in activities may also help. If a person fidgets a lot, try giving them something to occupy their hands such as a soft toy or a handkerchief.

- **Sleep disturbance**

Dementia can affect a person's sleep patterns. They may get up repeatedly during the night or become disorientated when they wake up. They may get dressed or try to leave the house. Disturbed sleep can have a negative impact on a person's wellbeing and can be particularly hard on their relatives, as their sleep is disturbed too.

- ❖ Make sure the person with dementia has plenty of daylight and things to do during the day. Their sleeping environment should be comfortable and provides a safe feeling.

- **Trailing, following and checking**

A PwD may follow their partner or carer around to be close to them.

Dementia can make people feel insecure and anxious. They may "shadow" the people near them as they need reassurance they're not alone and they're safe.

Perhaps they ask about deceased people, or want to go home without realising they are at home.

- ❖ Being with the person may reassure them. Keep close when you have tasks to carry out. Think carefully about what you tell the person when they are asking for someone from the past of someone who had died. Don't cause distress, sometimes it is better to comfort them by not telling the truth and talk about something else.

- **Shouting and screaming**

In later stages of dementia, a significant number of people living with it will develop more aggressive behaviour. They may scream, shout, have delusions (not based on reality) or use abusive language.

- ❖ This behaviour may be the response for not understanding what is going on. Involve the person in what is happening and explain what you are doing. Think about whether the environment could be causing the person distress or not meeting their needs.



- **Losing inhibitions**

Sometimes a PwD can lose their inhibitions and may behave in ways that others find embarrassing. Losing inhibitions can include being rude, saying things that are not appropriate, talking to strangers and undressing in public. This can be embarrassing and distressing for both the person with dementia and those around them.

- ❖ Try to stay calm and remember that they don't understand that what they are doing is inappropriate. It is unlikely they do this on purpose. It may help gently distracting the person and be aware of possible triggers for certain behaviour.

It can help to work out if there are any triggers for specific behaviour. For example:

- Do some behaviours happen at a certain time of day?
- Is the person finding the home too noisy or cluttered?
- Do these changes happen when a person is being challenged or asked to do something they may not want to do?

Keeping a diary for a few weeks can help identify these triggers. If changes in behaviour appear suddenly, make sure a health problem, pain or discomfort is not the cause.

Maintaining an active social life, continuing with activities the person with dementia has enjoyed or finding new ones, and regular gentle exercise can all help to reduce behaviours that are out of character.

4.5 Assisting persons living with dementia?

If you are a neighbour or citizen living close to a PwD, then you can do something for him or her! Someone with (early) dementia usually handles themselves fine, but sometimes they can use help from people in their environment.

You can support them and their caregivers in all sorts of ways. A small gesture or an hour of your time is often enough.

A few ideas to help your neighbour with dementia:

- ❖ Go visit the neighbour with dementia and drink a cup of coffee or tea with him or her.
- ❖ Go on a short walk or walk the dog together.
- ❖ Does your neighbour not like to walk? Maybe you can do some work together in the garden.
- ❖ Look at pictures from the past or sing songs together.
- ❖ Help the person with dementia to get groceries.
- ❖ Take the person with dementia to the gym or the community centre.



The caregiver is often heavily challenged by the combination of work and care but generally finds it difficult to ask others for help. They will often say "It's okay, I'll be fine" and don't want to be a burden to others. As a result, the quality of life for both the caregiver and the person with dementia will decline. But you can do something to support the caregiver.

A few ideas to support the caregiver of your neighbour with dementia:

❖ **Offer practical support**

Because it is often difficult to hand over care, offer practical support such as cleaning, mowing the lawn, shopping, buying a gift for a (grand) child or just a lift by car.

❖ **Take on time-consuming jobs**

Caregivers are often busy with arranging and planning. Maybe you can do some time-consuming jobs such as keeping track of finances, looking for a volunteer for chores around the house and finding the best day care for those with dementia.

❖ **Offer to go out with the caregiver**

Let a caregiver know they can count on you if he or she has time for themselves and wants to grab a terrace, go to the movies or go shopping together. Or maybe just for a walk.

❖ **Become a spare caregiver for a few hours**

Ask the caregiver what the PwD likes to do and take over the care for a short period to do fun things with this person. This gives the caregiver breathing space to do something for themselves



2. DEALING WITH DIGITAL COMMUNICATION

A growing number of web users around the world are living with dementia. People living with dementia and their relatives have various levels of digital literacy. They may be experiencing difficulties sequencing and processing information, reduced problem-solving abilities and thinking speed, judgment, vision and perception or problems with language and words.

A lot of information about dementia and, for example, local social or support initiatives are to be found on the internet. By creating websites that are more accessible to this growing group of users, designers can support PwD to help them and their relatives stay active and participating in the community as long as possible by following specific digital design [guidelines](#).

The EDEN project also presents a digital platform for learning and teaching materials headed against PwD, relatives, CSOs and HSCPs developed after the guidelines listed below: [Learning and teaching platform](#)

5.1 Dementia digital design guidelines

- [Include people affected by dementia](#)

This will help to understand, validate and meet real needs. It will also help improve empathy for whom you are designing. So make sure to:

- Include PwD and their relatives in all stages of design. Conduct primary research with them.
- Get feedback from PwD. Test, validate and iterate designs with representative users.
- Promote that your website is dementia-friendly and help reducing stigma.

- [Writing, words and terms](#)

People living with dementia may struggle with language, like remembering a word or terminology. Therefore:

- Use simple, clear and precise headings and labels.
- Avoid generic calls to action or complex wordplay and use unambiguous headings.
- Use explicit content. Make the purpose clear and content interesting.
- Use dementia positive language, 'living with', rather than 'suffering from', dementia. Be respectful.
- Avoiding using abbreviations and acronyms.

- [Layout, navigation and interface design](#)

People can struggle to remember things and become disorientated. Try to make navigation explicit and signpost a route back to the homepage, or the start. Therefore:

- Provide a clear link to 'Home', or the start.
- Use clear section breaks to make splits and stages obvious.
- Make hyperlink styles clear.
- Avoid splitting tasks across multiple screens and hiding navigation off-screen.



- **Colours and contrast**

Each type of dementia can damage the visual system in a number of different ways. Perceptual problems that cause misinterpretation can also occur. And as people get older, normal vision will change simply due to ageing. This can mean that age-related visual decline may affect both the person with dementia as well as their relatives. So:

- Use high contrast colour schemes to improve readability.
- Use plain backgrounds for textual content, rather than patterns or images.
- Avoid the use of blue, especially for important interface elements.

- **Text and fonts**

Make letter shapes and words simple and easy to perceive. This improves readability and comprehension for all people on all computer devices. Tips to make words more readable include:

- Using an open source sans-serif typeface. The simplicity of these letter shapes is more readable.
- Using a larger text size (and higher contrast) to provide more information to the eye.
- Using bold text alongside clear, short statements. This is useful to highlight important information.
- Avoiding unnecessary multiple fonts. This may make the interface and content confusing.

- **Images and multimedia**

Videos and images can be misinterpreted for real situations and people. Keep images and multimedia therefore simple, relevant and closely related to the content.

- Images should be engaging and meaningful.
- Provide subtitles or transcripts for video and audio content.
- Use simple and familiar playback controls.
- Pictograms and icons can aid recognition and function of user interface control.





3. TIPS & TRICKS POSTERS

Collaboration and support around and with a person living with dementia

Within health the health and social care sector, it is increasingly acknowledged, that good and high quality care should be developed and implemented around the concrete needs and wishes of the person who needs care. How the person manages their health and disease themselves and how their environment (family, neighbours and friends) is involved.

Relatives and other (professional) caregivers offer care and support in all sorts of ways and have a lot of knowledge about the person living with dementia, which needs to be taken into considering on a continuous basis. Working together is therefore a logical step.

Connecting in cooperating with the person with dementia and his/her family provides more involvement, more possibilities for care and support and more job satisfaction for health care professionals, civil society organizations and volunteers.

In the needs analysis, relatives expressed their wish for more recognition in their caregiver role but also for the PwD: Getting to know this person and having eye for personal needs. Knowledge about local support options and information about dementia in general were also wanted.

Based on these wishes, the following pages show useful tips on how to engage the community and to improve interaction and collaboration with involved parties around the PwD.

- ❖ Practical tips for HSCPs in their daily interaction with informal caregivers to enhance good collaboration.
- ❖ How to help a caregiver of a PwD. Practical tips on providing help and support to prevent the caregiver from becoming overburdened.
- ❖ Volunteers are essential for the support and care of PwD and their caregivers. Practical tips on how to attract volunteers.
- ❖ Keeping your volunteers happy and committed so they will stay with your organization is a constant cycle. Practical tips on how to retain volunteers.
- ❖ Today's students are the caregivers and health professionals of the future. How to prepare them? Practical tips on how to motivate and educate students to work with dementia.
- ❖ Engaging your community. Practical tips to support encourage and inspire people to create positive changes in their community.
- ❖ Information about what embracing dementia in a community means and what points and actions to think of to achieve this.
- ❖ Social Plan: who is who in your community and for the person with dementia? Create your own social plan for your network and support.

HEALTH CARE PROFESSIONALS IN THEIR DAILY INTERACTION WITH INFORMAL CAREGIVERS



8 PRACTICAL TIPS

Suppose your parent, partner, child or close friend needs care. Then you would like healthcare professionals to listen carefully to you and match your wishes. Are you such a healthcare professional who talks with caregivers?

Below are 8 practical tips that a professional caregiver or nurse can use right away in their daily work. Good cooperation with the informal caregiver delivers a lot. For "your" client, for the informal caregiver and for yourself as a healthcare professional.

What would you like yourself?

1

Fun: many differences

Not everyone is the same: have an eye for diversity, social background and connect with the relationship and habits that the client and caregiver have.

2

Valuable track info

Take advantage of the valuable information that the caregiver can provide about the client from his own experience.

3

Customization: first ask, then offer

Ask what is needed and provide more information, for example. Or discuss what volunteers can do so that the caregiver can take a breather.

4

Handy: one contact person

Make sure you have a permanent contact person in the family. The caregiver also likes to have one permanent healthcare professional who is easily accessible by phone or e-mail.

5

Pitfall: avoid misunderstandings

Note agreements with the family in the care plan and regularly coordinate whether the agreements are still mutually satisfactory.

6

Clarity: be open

Offer a lot of room for personal wishes and be open about what everyone's role can be.

7

One to one contact

Ask caregivers regularly how they are doing. And don't do that in the 'pass by', take your time.

8

Show the way

Make sure you are aware of the support options for informal caregivers, at the institution where you work or at local society organizations in the neighborhood.



HOW TO HELP A DEMENTIA CAREGIVER

11 PRACTICAL TIPS



Caregivers take care of someone with dementia in addition to all their other daily activities and obligations. Social contacts can become less and they often find it difficult to ask for help. It is nice if someone occasionally takes over something. This can be practical matters, but also just being there regularly, listening and thinking along can be valuable. If a friend or family member is caring for someone with dementia, it's important to offer all the help and support you can.

1

Not alone

Let them know that they are not alone. That you sympathize, think of them and are there when needed.

3

Be a friend

Caregivers will often distance themselves from family and friends but they do need contact with the outside world. Phone calls, texts or emails are fine, but nothing beats a personal visit to lift a caregiver's mood.

5

Take dementia seriously

Dementia is a serious disease, but not always clear to the outside world. People with dementia can often disguise or deny their illness. So take the words of the caregiver seriously and offer your support.

7

Don't judge too hard

Be careful with criticism or well-intended tips and advice. Dementia is a difficult disease which is different for everyone. It will lead to many changes over time.

9

Expand the network

See if you can expand the network of people who want to help the relative to take care of the person living with dementia. Maybe with the help of family, friends, neighbours or volunteers.

2

Recognize the signs

Recognize the signs of caregivers stress and encourage the caregiver to focus more on their own health & well-being.

4

Be a good listener

Venting frustrations about caregiving can be a great stress reliever. Listen to the caregiver's story and concerns without judging. They are losing someone and this is a slow and difficult process.

6

Understanding

The situation is often more complex than you think. Find information and videos that show what it is like to have dementia. By increasing your knowledge you will understand the situation better.

8

Practical tasks

Sometimes it is difficult to hand over personal care (like showering or dressing). So take over practical or time-consuming tasks like finances, cleaning, walking the dog or doing groceries.

10

Show your gratitude

The caregiver may be a sibling looking after your parent. It is important to express gratitude and recognition of their hard work and sacrifice. A card or a simple "Thank you" can go a long way.

11

Offer a helping hand

Many caregivers find it difficult to ask for help, no matter how much they may need it. So make the offer. When you do, be specific. Helping out with even the most simple chores can give the caregiver more quality time with their partner or take a break.



HOW TO ATTRACT VOLUNTEERS

9 PRACTICAL TIPS



Volunteers are essential for the support and care of people living with dementia and their caregivers. Volunteering for them is a fantastic way to support a dementia-friendly environment and it will make an impact in the community. Finding and keeping great volunteers however, can be a constant effort and challenge. **So how to attract volunteers?**

1 Spread the word

Let everyone know that you are recruiting volunteers and be clear about the reasons why and for what you are recruiting. The reason why also determines mostly who you want to recruit. If you want to recruit everyone, you will not reach anyone!

2 Be concrete

State clearly why you are looking for a specific volunteer, why it is important to the organization and what you have to offer. Give a concrete description of the task/expectations so the volunteer knows what they are signing up for.

3 Treat is as if it is a regular job

Potential volunteers might look at the title of the position as if it was an employment opportunity. Even "retirees" like to be recognized with a named role. Create a contract for the volunteer with their rights and mutual agreements.

4 Be creative

Make your description and job title fun, a little flair gets people's attention. Don't forget that volunteers choose to help during their spare time, so make the volunteer opportunity special and about making a difference.

5 Advertise effectively

Create simple, catchy flyers to spread in high traffic locations like schools and on social media. Social media is the most efficient and effective way to spread your announcement. Use correct information and keep your website up to date.

6 The right match

Match volunteers with tasks that fit their skills or something that they enjoy. By doing so you give value to their effort making their experience worthwhile. A volunteer who feels truly needed, is much more likely to stay.

7 Don't forget students

Especially students from care related studies are often interested in the subject dementia. Volunteering is a great opportunity to learn about people with dementia in practice. Talk to school coordinators, create flyers and hand them out in strategic student locations.

8 Be welcoming

Every new volunteer is an asset to the organization. Take good care of them! Give them a warm welcome, take the time to get acquainted and discuss the tasks and expectations.

9 Engage the community

Recruiting volunteers has changed the last years to something far more dynamic. Your image can determine whether volunteers would like to work for you or not. Think about creating something fun to engage the community like an open house or contest and get the word out.



HOW TO RETAIN VOLUNTEERS

10 PRACTICAL TIPS



You found the right volunteer for the job! But what you don't want, is having volunteers today and none tomorrow. Getting volunteers to sign up is not the final step, it is a constant cycle. Keeping them motivated and engaged is a big challenge.

So how to keep your volunteers happy and committed?

1 Be flexible

Be flexible while creating tasks. Allow your volunteers' own schedules and create opportunities for those who want to volunteer temporarily or less frequently.

3 Share experiences

Every person is unique, every person with dementia is therefore their own individual with their own behavior. Make time for your volunteers to share experiences to get a better understanding and create new ideas.

5 Making a difference

Show volunteers how their work makes a difference. This makes them feel connected to the cause, which is vital for volunteer satisfaction. Let people with dementia and their caregivers talk about how meaningful the support is to them.

7 Communicate

To feel part of the team, keep your volunteers in the loop about the organization and upcoming events and initiatives. Encourage questions and feedback.

9 Help them grow

Treat volunteers as seriously as you would a paid employee. Manage them with respect and empower them to have a rewarding experience. Stimulate development and let them meet other people with common goals.

2 Training

Ensure your volunteers are well equipped by giving adequate training and materials. Don't make them feel like they've been thrown into the deep or don't fully understand.

4 Build a connection

Give your volunteer time and space to gain trust and build a connection. A person with dementia sometimes needs time to adjust to the new situation and to the volunteer.

6 Get to know them

Volunteers devote their time and want to build a relationship with the organization and cause. Pay attention to your new but also existing volunteers. Strengthen your relationship, express your appreciation (remember their birthday!) and talk individually once in a while.

8 Share successes

Show your volunteers the difference they make and highlight their contributions and successes. No motivation is greater than making a positive contribution to society.

10 Thank you!

It might sound like a no-brainer but appreciation matters! A simple heartfelt "thank you" can boost confidence and make volunteers feel good. Without their efforts your organization will not be able to achieve its goals.

If you invest time and energy into making volunteers feel invaluable, they're likely to make a long-term investment in you.



HOW TO MOTIVATE AND EDUCATE STUDENTS TO WORK WITH DEMENTIA

6 PRACTICAL TIPS



Today's students will be facing a large amount of people with dementia in the future. Whether or not these students enter the healthcare field, they will certainly encounter forms of Alzheimer and dementia in their surroundings. Lack of knowledge and mistaken beliefs will only increase the sense of stigma about dementia.

To educate students and to positively shape their attitudes about dementia they will understand dementia from the point of view of those affected. As well as to respect not only what has been taken away by the illness, but also what remains.

So how to educate and stimulate our students and how can they make a difference?

1

Encourage
volunteering

Students **do their best work** in the community **when it is relevant** to their academic skills and interests. To encourage more students to volunteer, we need to appeal to these skills and interests.

2

Dementia-friendly
e-learning

In some **places and schools**, specific dementia-friendly e-learning are developed to ensure that students already learn during their education how to cope with people with dementia. This could enhance the awareness and will prepare them for a future of working or dealing with dementia.

3

Professional
for a day

Offer the **opportunity** to spend a day with a **professional** who works with people with dementia. This way they experience first-hand the challenges of dementia but also the rewards you get from working with people affected by dementia.

4

Contact study
coordinators

Connect **social issues** with students of relevant studies. Contact local coordinators at schools for possibilities. Perhaps a specific issue can be linked to a learning assignment. Involve the students (where possible) with the description of the assignment. This makes them feel involved and responsible. If this proves to be successful, it may become a structural part of the study.

5

Young teaching
old

Students **giving interactive** lectures to elderly with dementia can be a stimulus for both. Students learn from the elderly and can improve their presentation skills. The elderly can share their knowledge and might learn something new, which increases their sense of well-being. Encourage participants and students to engage in a conversation with each other, it's a win-win situation! The people with dementia may not all know what they did afterwards, but they did enjoy it. Possible topics: biology (the human body or nature) or history (local traditions or art).

6

Buddy projects

Linking a **student as a companion** for a person living with dementia and their caregiver can be interesting for students. To make or maintain the connection with the outside world by taking a walk or work in the garden. Or just by drinking coffee together. Educational for students and the caregiver is relieved for a while. But make sure there is a positive connection between both!



TIPS ON ENGAGING YOUR COMMUNITY

10 PRACTICAL TIPS



Connected communities where people work together, are more resilient against local and global issues and better equipped to tackle challenges and bring about positive change. Supporting, encouraging and inspiring people to create positive changes in their community is important, but how to do so?

1 Get a variety of perspectives

A neighbourhood is full of people with all sorts of skills and knowledge, get them involved! Community engagement is a great way to tap into local knowledge and solve problems. Not everyone will participate to the same degree, but everyone should have the opportunity to take part in some way, even just to share your thoughts.

3 Back up funding bids

Most funders will only take a community project serious if you can prove that there is a 'need' for it. Be able to show that people support the project, and ideally that they've taken part in its design. Show funders how successful it is through positive feedback from the wider community.

2 Get local help

It doesn't matter how big or small the project or idea is; if it's going to make a difference to your neighbourhood you'll need some help and probably volunteers. Holding a community engagement event will give you the chance to sound out people about how they think about the neighbourhood and find out who is interested in helping.

4 Inspire local people

Community engagement isn't just about asking people what they want — it's also a chance to inspire them with new ideas and ways of doing things. Show people the variety of possibilities and let them use their imagination.

Communication is the art of connecting with people and vital for community engagement. Using the following tips for successful communication will increase chances of people joining in.

1 Be inclusive

Create opportunities for people to participate in a meaningful way. Let them share their stories, ideas and opinions. Powerful and memorable experiences happen when people get involved in something together.

3 Be sociable

Create moments for people to be sociable and open for conversation. Encourage people of all ages and backgrounds to work together, because there is a lot to learn from one another.

5 Be playful

Break through cynicism and make humour a key part of it all. Go outside, play games and find creative ways to find out what people in your neighbourhood really want without using survey forms and taking meeting minutes.

2 Be optimistic

Focus on the positive and believe in success. It's no fun joining in if you are going to be preached at, so make sure you encourage people, use positive language and celebrate the good things that are happening.

4 Be open

People are individuals and as such, have differing needs and approaches. Be open to this by providing a variety of ways for people to find out more, get involved and understand the project and where it's heading.

6 Be imaginative

Encourage people to navigate their own way, make their own discoveries and identify their own connections. Try to appeal to all the senses by making use of art, storytelling or even puppetry to add a different dimensions.

Read more on edenprojectcommunities.com



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Embracing dementia in a community means:

Focus on the inclusion of people living with dementia (and their caregivers).
Embrace dementia!

Maintaining independent living as long as possible by providing supportive and meaningful community engagement.

Businesses, local government services and emergency responses are dementia educated and able to respond effectively to customers with dementia.

Empowering people with dementia and recognizing their contribution.

Ensuring that (local) activities include people with dementia.

Specialized memory loss support and services.

Health care that ensures early diagnosis and the best quality care; patient and caregiver support.

Challenging stigma and building awareness.

Easy to navigate physical environments and accessible public transportation.

People living with dementia feel supported by individuals, businesses and local governments. Community members are educated and understand that a person with dementia may sometimes experience the world differently.

WHO'S WHO IN YOUR COMMUNITY?

MEDICAL

SOCIAL

Elderly
Psychologist

Neighborhood
nurse

Social Support
Act advisor



Specialist
geriatric
medicine

General
coordinator
community

Lifestyle
advisor

Independent
client support

Spiritual
counselor

Dentist



Volunteer
coordinator

Caregiver
supporter

Family
friends

Citizen

Neighbors

Volunteers

Practice
assistant

General
practitioner



Social
worker

Practice
nurse
elderly care

Paramedics

Dementia
case manager

Elderly
advisor

Housing
corporation
employee



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4. LEARN FROM WHAT WORKS

Share information & good practices, work together and learn from each other!

The next pages show some examples of initiatives on a local or regional level from all project partners.

Good practices The Netherlands

Alzheimer café

The concept of the Alzheimer Café was established in the Netherlands as a vehicle for providing a welcoming atmosphere in an accessible location for all people with or affected by dementia.

The first Alzheimer Café took place in 1997 in a collaboration between Dr Bère Miesen and the regional branch of Alzheimer Nederland in north Zuid-Holland. There are now 230 Alzheimer Cafes run by volunteers in the Netherlands with around 35,000 unique visitors each year.

Although people with dementia and their families, friends or carers are core attendees, others with an interest in dementia, such as students, local politicians, the media and those who want to find out more about dementia can attend an Alzheimer Café.

The event usually begins with a discussion or presentation on a particular theme followed by a less structured period where those attending can share their experiences, thoughts and ideas with others. To support various communities in the country, Alzheimer Tea Houses were introduced for those whose first language is Moroccan or Turkish.

Due to their success in the Netherlands, Alzheimer Cafes have been adopted in more than 15 countries around the world, sometimes as part of a wider dementia friendly community initiative. The concept has been introduced in countries such as Argentina, Aruba and Curaçao where broader dementia friendly community projects do not currently exist.

To support this international implementation, Alzheimer Nederland has developed a guide for setting up an Alzheimer Café.

Manual Alzheimer Café





DemenTalent

DemenTalent aims to build upon the talents of people with dementia, offering them a voluntary role within their community based on their abilities.

It is all about empowering people with dementia. Look at their talents and what they can do, every person is different and has his or her own preferences and wishes.

The focus is on what a person can and wants to do, not on what they no longer can do. Make use of these talents in society by deploying PwD as a volunteer. This makes PwD feel useful and valuable, the connection with society is maintained and they can continue to function independently for longer.

The benefits of this project, which was originally launched in 2012, are two-fold as PwD benefit emotionally and communities are presented with images of PwD as capable and talented individuals. This volunteer work can be individual but also in groups. Examples are working in a garden, a nursery, sports club, museum, school or a football club.

Website of DemenTalent



Stichting Kameraad

Kameraad offers support through a "buddy" to PwD and their caregivers.

Participants are visited and supported by students from the HBO Social Work study program and creative-agogic support is offered. The students of Kameraad look at the individual wishes and needs of the PwD and their caregivers and work with possibilities instead of impossibilities.

Kameraad works together with the social network and, where possible, connects to strengthened this. This so that the caregiver has a wider support group at his or her disposal. Activities are always tailor-made and in close coordination with those involved.

Their aim is to make the life of the PwD and their loved ones a little more fun and easier.

Website of Stichting Kameraad





Good practices – Spain

Age Friendly Basque Country

Euskadi Lagunkoia or AF Basque Country project is an initiative which is being carried out from the Department of Employment and Social Policies of the Basque Country and Matia Institute since 2012. It is based on the "Age friendly cities and communities" program and enables older people to live in "age-friendly" villages and cities, by removing physical obstacles and barriers as well as by tapping their potential as protagonists and leaders of the project. So far, more than 60 municipalities in this region joined Euskadi Lagunkoia to improve the quality of life of their citizens.

Recently, different institutions have included the concept dementia in the friendly paradigm, transferring the age-friendly theory to dementia issue. In doing this, it becomes a key strategy to facilitate the inclusion of PwD in society. It enables PwD to actively participate in community activities by facilitating them to remain connected to people important for them as well as it helps to provide appropriate support to those who can no longer look after themselves.

Dementia friendly approach was included in Euskadi Lagunkoia in 2015 in order to promote dementia friendly communities. After a comprehensive study, in which professionals, PwD and relatives participated, some action programmes were developed: the Dementia Friendly Community Guide and the Dementia Friendly Housing Guide. The Dementia Friendly Guide aims at citizen awareness and provides guidelines about how to help PwD in their daily life.

Additionally, the Dementia Friendly Housing Guide aims to provide guidelines for adapting housing to the needs of PwD and their caregivers. The main idea is to help people to identify which elements that can be changed in the environment to generate changes in behaviour and make day-to-day life easier. This broad initiative aims at helping both by understanding dementia and provided people information to cope with dementia. This to help social inclusion of PwD and to support people to be able to cope with the future.

[Website Age Friendly Basque Country](#)





Age Friendly Business Program

The Age Friendly Business Program was developed under the Dementia friendly approach to promote dementia friendly communities. Specifically, this is an action program oriented to help businesses, shops and establishments.

For this, educational, training and self-assessment materials to participating businesses are provided to make the environment and services friendlier with older people, including PwD.

In this sense, it is about to understand and cope with dementia. Information about how businesses can provide quality services for older adults affected by loss of mobility, vision and hearing impairments and dementia was included.

Regarding dementia, the program is specially focused on helping those business owners and managers to detect, address and promote the autonomy of those clients with mild cognitive impairment.

Website Age Friendly Business Program





Good Practices - the UK

Dementia Adventure

Dementia Adventure is a charity dedicated to supporting PwD to get outdoors, connect with nature, themselves and their community, and retain a sense of adventure in their lives. By raising funds, they reduce the cost of the fully supported dementia holidays and can make a holiday possible for somebody who might otherwise not be able to afford to take a break.

They can also provide free dementia training for family carers and do research into the benefits of outdoor activity.

Through their training and consultancy services they work with other organizations to help equip them with the evidence, skills and confidence to give people greater choices and live better with dementia.

Their work is grounded in research and they collaborate with academic institutions and the public sector to advance and contribute to the growing evidence-base for being physically active within nature and the benefits it brings to PwD.

Since 2009 they have trained thousands of individuals and organized many supported dementia holidays—making a huge difference to people with dementia and their carers.

[Website Dementia Adventure](#)



Touchstone's BME Dementia Service

Touchstone's BME Dementia Service aims to raise awareness of dementia in BME (black and minority ethnic) communities and to ensure that all PwD are properly supported. The idea behind this initiative is to break down the barriers that exist about dementia and bring it out into the open so that people can access the help they need.

What they do?

- Visiting day centers, community groups and religious centers to talk about dementia and tackle the stigma that surrounds dementia.
- Speaking to people in their own languages and offering culturally appropriate information in different languages.
- Running a monthly dementia café in Harehills, called Hamari Yaadain.

Since 2013, when it has been founded the BME Dementia Forum, they have led a group of BME dementia workers in Leeds to improve services for people with dementia and their carer's, specifically for people from BME communities.

[Website Touchstone](#)





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Rainbow Café

Based in Brighton, the Rainbow Café is new initiative for Lesbian, Gay, Bisexual, Transgender or Queer (LGBTQ) PwD or memory loss and their friends, families and carers.

LGBTQ people face additional barriers when it comes to dementia, with settings making the wrong assumptions about someone sexuality or gender identity. On its own this can be upsetting, but when someone is also faced with a dementia diagnosis it can really make things worse. Rainbow Café offers a safe space for LGBTQ people living with dementia and through it they also work with others to ensure that the needs of LGBTQ people are really understood.

The Rainbow Café was opened by the Mayor Councilor Mo Marsh and with a performance of the awarding winning play 'The Purple List: A Gay Dementia Venture'. The play captured the story of a same sex couple, whose life is interrupted with a diagnosis of dementia. The performance was followed by a question and answer session with a panel made up of services supporting dementia. The panel acknowledged that there is still work to do in terms of supporting LGBTQ people living with the condition and Switchboard were praised for their efforts in responding to the need.

[Website Rainbow Café](#)





Good practices – Italy

Casa Viola

Casa Viola is a multidimensional project aimed at offering meeting opportunities, information and training programs, psychological support and specific meetings with specialized nurses, as well as promoting scientific activities, tailored for PwD and their caregivers.

Casa Viola services are free and they are focused on:

- 1) Avoiding caregivers' isolation offering a place where caregivers can meet each other; participate in aid groups, activities and workshops; receive the support of volunteers and psychologist.
- 2) Promoting training activities tailored for caregivers in order to enhance their well-being. Examples of proposed activities are: courses to learn relaxation and body awareness techniques; workshops dedicated to good, healthy and protective nutrition; art-therapy workshops; and creative workshops.
- 3) Offering counselling services; legal and social assistance.
- 4) Promoting the "Caregiver Academy" project: a specific training program tailored for caregivers of PwD organized in 12 meetings. During the meetings caregivers are educated about the dementia syndrome-characteristics; how coping with the disease; how to develop communication, care and stress management strategies; how promoting the legal protection of the elderly and their families.

Promoting the "Dementia-Friendly Community" in the Municipality of Muggia (Trieste, Italy). The De Banfield Association, the Municipality of Muggia and the "Azienda Sanitaria Univesitaria Giuliano-Isontina" are working together in order to train the community (e.g. retailers, public employees, associations, health care professionals and police) to include PwD in the social activities and life.

[Website of Casa Viola](#)

CASA  VIOLA
DE BANFIELD



Mind in Training

Mind in Training is a Cognitive Stimulation Project and an example of networking among different stakeholders, formal and informal services (hospitals, social services, students, teachers, civil society associations), in order to enhance the quality of life of people living with an early stage of dementia and that of their relatives.

It shows that it is possible to promote the intergenerational exchange and communication, as well as increasing the education and information of new generation about dementia and its characteristics.

The project involves:

1. 10 people in the pre-clinical phase of mild cognitive impairment.
2. A group of high school students from the “Istituto Tecnico Industriale Statale J.F. Kennedy” (ITIS J.F. Kennedy) of Pordenone who collaborated in the creation of an Application Program or “APP” based on cognitive exercises tailored for people affected by dementia.
3. Relatives/caregivers of the 10 people selected for the study.
4. The Associazione Familiari Alzheimer-Onlus of Pordenone members who promoted the cognitive stimulation exercises and relatives/caregivers support.
5. Professionals of Azienda Sanitaria Friuli Occidentale (AS FO) (previous “Azienda per i Servizi Sanitari n.5” – ASS 5) who selected participants and monitored the cognitive stimulation effects.

Once the APP was created, it was installed in 10 tablets and a group of high school students from the ITIS J.F. Kennedy trained the selected participants and their relatives to use it during 10 meetings. Participants were invited performing the cognitive exercises daily at home using the APP; twice a week they also received a specific cognitive stimulation at the AFAP association. During these sections of activities, the relatives were involved in aid group meetings. All cognitive exercises performed by participants were recorded in a specific database, and all data was monitored and analysed by the professionals of AS FO (previous ASS 5). Overall, the cognitive stimulation period lasted 40 weeks. Preliminary results of the project showed that, through the use of innovative information technologies, various skills have been stimulated and participants’ memory abilities and socialization improved. Across the different stakeholders and they all working together, a new effective collaboration emerged. Furthermore, the use of this new technology allowed to create a sort of bridge between generations in a mutual exchange of knowledge and collaboration. A way of bringing the young generation closer to health and social issues that could involve them in the future. Relatives /caregivers reported satisfying improvements in memory abilities of participants, as well as improved information and knowledge in coping with the disease.

[Website Mind in Training](#)





Good practices – Denmark

Dementia Friendly Odense – Focus area 1 in Dementia Strategy

The Municipality of Odense, the third largest city in Denmark (+200.000 inhabitants), has a strong focus on developing the dementia friendliness throughout the city. At the same time, Alzheimer Society Denmark initiated a nationwide initiative to ‘educate’ dementia friends everywhere. Inspired by Dementia Friendly Crawley in the UK, the subcommittee for older persons decided on an ambitious plan to raise general knowledge and awareness and facilitate dementia friendly activities such as dementia friend courses, articles and public events.

There are specific initiatives for libraries, bus drivers or sports and leisure centers, where a combination of awareness campaigns and changes in physical surroundings and services aims to make accessibility easier. There are also network activities, aiming to connect services for all people with knowledge on dementia, and with the experts and staff, who in later stages meet PwD, when they need more help and support to cope and manage their everyday life.

To facilitate the initiative, a project manager was appointed with the responsibility for developing activities, facilitating cooperation between public, private and civil society, and educating dementia friends with courses and dementia friendly instructors.

This has resulted in more than 3000 dementia friends now, in all types of jobs, businesses and ages. The aim was to spread knowledge wherever PwD meet other kinds of service or cultural staff, but also spread knowledge of dementia to everyone, for instance middle school children have been receiving dementia friend-courses. There are dementia-friendly bus drivers, sports instructors, all staff members at libraries, and a number of other businesses in Odense.

There is also an annual Dementia Awareness day, where over 120 persons with dementia, spouses and relatives etc. participates and learn about coping with dementia, and still having a good quality of life.

The aim is to make changes, big and small, that makes it easier to participate in activities, in life and social, cultural and commerce for people living with dementia. This is very much a process of co-creation, or “untidy conversations” as the Dementia Friendly Crawley calls it. Different perspectives, needs and organizations get together and discuss how to improve inclusion and general quality of life for persons with dementia.

From this, initiatives to make access and inclusion easier have been developed in sports centers and swimming courts. Finding your way and getting help can quite easily be more understandable. There are also dementia-friendly initiatives with libraries, churches, music halls and more, ‘normal’ services.

An example is the continuing dialogue with the management in the bus companies, on how to make both services, webpages and the actual experience of riding busses more flexible and understandable.

[Website Dementia-friendly Odense](#)





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5. RESOURCES AND WEB LINKS

www.alz.co.uk
www.alzheimers.org.uk
www.dementiaallianceinternational.org
www.samendementievriendelijk.nl
www.alz.org
www.nhs.uk
www.mantelzorg.nl
www.thoughtfarmer.com
www.helpguide.org
<http://scott.london/articles>
www.edenprojectcommunities.com
www.rikwilliams.net/digital-guidelines

MAP YOUR OWN COMMUNITY

MEDICAL

SOCIAL

Elderly Psychologist

Neighborhood nurse

Social Support
Act advisor

Lifestyle
advisor

General coordinator
community



Specialist geriatric
medicine

Spiritual counselor

Independent
client support

Volunteer
coordinator

Dentist



Caregiver support

Practice nurse
elderly care

Family
friends

Citizen

Neighbors

Volunteers

Practice assistant

Health center

General practitioner

Paramedics

Community
Center

Social worker

Housing corporation
employee

Dementia
case manager

Elderly advisor

