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EDEN

Community Collaboration Concept

Embracement and Inclusion



The Project Partners in the Embracing Dementia project are:



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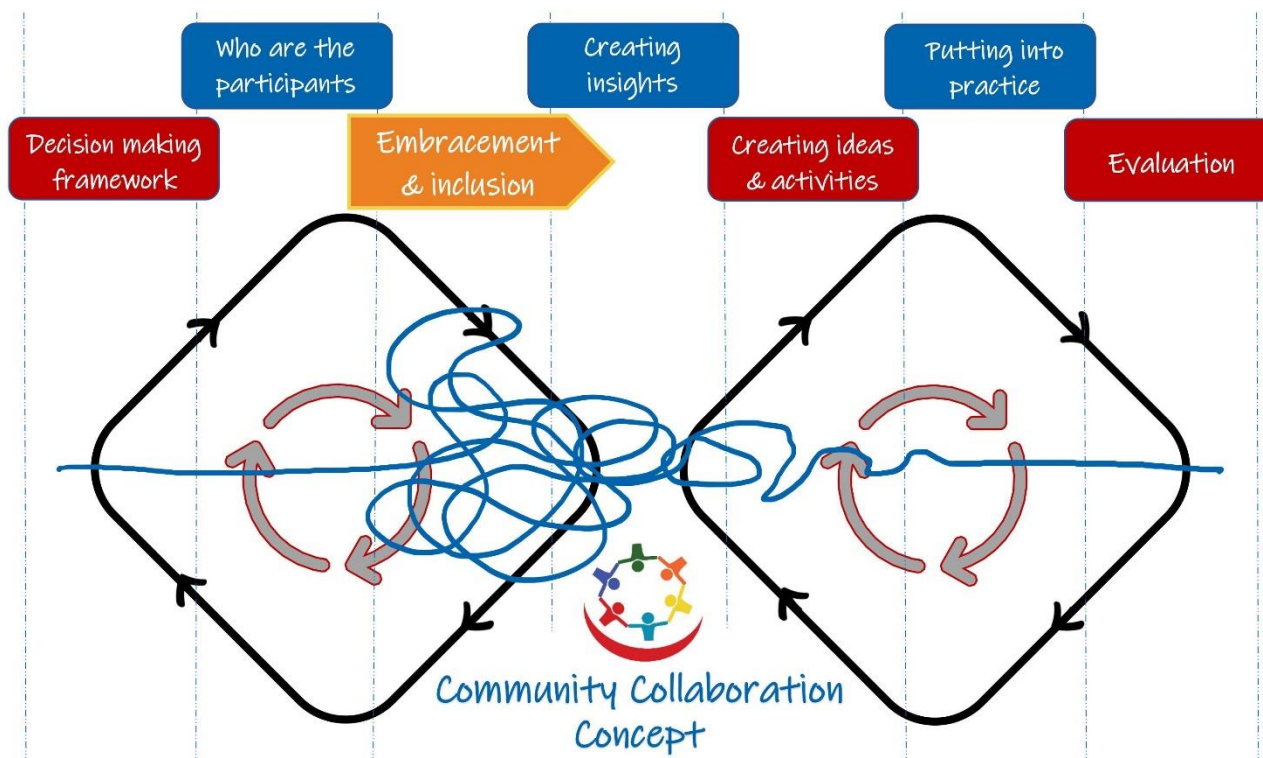
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Embracing dementia and inclusion



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>

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.



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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





Understanding 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.

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.



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!

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



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.

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