MOVE YOUR HANDS FOR DEMENTIA

Co-funded by the Erasmus+ Programme of the European Union

Recommendations for EDA Leaders

Co-funded by the Erasmus+ Programme of the European Union

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Recommendations for Adult Educators (EDA) Leaders

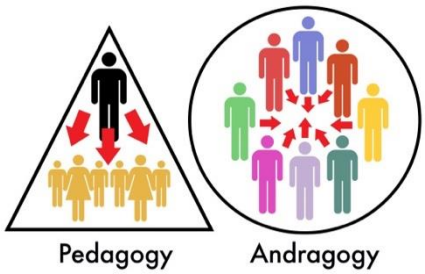
Methodological Introduction on Adult Learning

***Responsible partner**: Emphasys Centre (CY)*

The chapter in brief: "*Anyone who stops learning is old. Anyone who keeps learning stays young".' Education and the ability to continue learning are fundamental human rights. They are crucial to the personal development of the citizens but they are also key to the promotion of a more equal society, increasing democratic participation and reducing widespread inequalities. This part aims to provide an introduction to adult learning methods and the characteristics of adult learners.*

An important part of being an effective educator involves the ability to understand how adults learn best. This knowledge can support trainers to meet the needs of their learners, however it is important to keep in mind that no single theory can be applied to all learners, as every person is unique.

Andragogy refers to the art and science of adult learning, and it is one of the most influential theories in the field of adult learning (Kearsley, 2010). The term derives from the Greek language, means man (adult)-leading, and analysed the specific requirements and approaches for adult learning, by having the adult learner on the centre of this approach as an autonomous and self-directed individual.



Specifically, Knowles (1984) suggested 5 assumptions about the characteristics of adult learners:

✓ **Self-Concept**

As a person matures his/her self-concept moves from one of being a dependent personality toward one of being a self-directed human being.

✓ **Adult Learner Experience**

As a person matures, he/she accumulates a big collection of experience that becomes an increasing resource for learning.

✓ **Readiness to Learn**

As a person matures his/her readiness to learn becomes oriented increasingly to the developmental tasks of his/her social roles.

✓ **Orientation to Learning**

As a person matures his/her time perspective changes from one of postponed application of knowledge to immediacy of application. As a result, his/her orientation toward learning shifts from one of subject-centeredness to one of problem centeredness.

✓ **Motivation to Learn**

As a person matures the motivation to learn is internal.

Therefore, the recommendation is that adult education/training actions start with activities that promote self-directed learning. As a model for adult education, andragogy is characterized by a methodology that promotes learners' active participation—through flexibility (also in the organization of the curriculum) and focusing on the process, instead of the emphasis on content, aiming to meet each adult's specificities.

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Finally, the training context should reflect practices of mutual respect, cooperation, mutual trust, support and help, openness and authenticity and even pleasure, always involving all participants, i.e., students and teachers/trainers. According to the andragogic model, the favourable climate for learning has as characteristics comfort, informality and respect, thus ensuring that the student feels safe and confident. As for the trainers, they are considered facilitators of learning, and as such, their relationship with the students is horizontal, with dialogue, respect, collaboration and trust as the main characteristics. Thus, it is important for all adult educators to keep those principles and guidelines in mind when designing or delivering adult education training, in order to ensure maximum learner engagement and motivation.

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Introduction

***Responsible partner**: ASL TO3 (IT)*

The chapter in brief: *Scientific literature about dementia and adult learning methods provide contents and approaches to improve integrative communities.*

Policies for People Living With Dementia

WHO and Alzheimer's Disease Internationale defined dementia as a public health priority (WHO, 2012 and ADI, 2019).

Dementia prevention and diagnosis could be difficult partly due to cultural beliefs about aetiology but also for the antisocial behaviours, which produce significant stigma leading to stereotyping of all people with dementia as somehow falling into one undifferentiated category. A cause of stigma and prejudice, people may be more reluctant to talk about it, which contributes to a delay in diagnosis and low priority given to dementia care services.

Because of the great impact on the welfare, mental health, physical health of individuals and the cost for governments, it is vital to roll out programs to address stigma and promote Adult lifelong learning. Programs need to be informed by high quality research evidence. Policies need to be:

- **Evidence-based**,
- **Cost-effective**,
- **Sustainable and affordable**,
- Taking **public health principles and cultural aspects** into account

An epidemiologic focus

Dementia prevalence will double in 2030 and more than triple in 2050. Today, worldwide around 50 million people live with dementia, and this number is projected to increase to 152 million by 2050 (Livingston et al. 2020). MYH4D Recommendations aim to facilitate EDA Leaders, adult educators who provide training about dementia and other stakeholders to cope with the impact of dementia.

Since studies show that one-third of dementia cases refer to modifiable factors (such as smoking, hypertension, obesity, diabetes, depression, physical inactivity, low schooling, isolation and cognitive inactivity), a way to reduce the prevalence of dementia might be to modify lifestyles and to improve quality of life (WHO, 2019). The presence of modifiable risk factors means that it is possible to delay or slow cognitive decline or dementia giving people information and using a public health approach to face this health priority. Policies and strategies for dementia prevention should address the full range of dementia-specific factors including social isolation and lack of cognitive stimulation. Interventions focusing on modifying individual behaviour and lifestyle may represent a promising area in dementia prevention.

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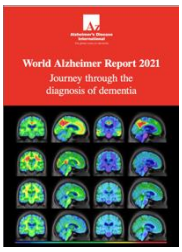
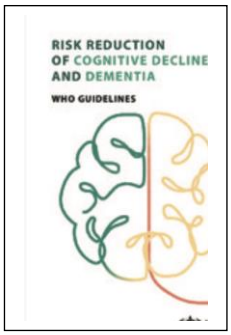


To know more:

As stated in the World Alzheimer Report 2021 *"Dementia is now the 7th leading cause of mortality globally and, as we know from previous World Alzheimer Reports, one of those with the highest cost to society. There is a perfect storm gathering on the horizon and governments all over the world should get to grips with it".* The Report focuses on the crucial and timely subject of diagnosis. Diagnosis is still a major challenge globally, with those who seek a diagnosis often experiencing long wait times, if they are able to receive a diagnosis at all. Societal stigma, self-stigma and clinician related stigma also exacerbate what is already a difficult journey.



To know more:

The WHO Guidelines on risk reduction of cognitive decline and dementia (2019) provide evidence-based recommendations on lifestyle behaviours and interventions to prevent dementia. Today, worldwide around 50 million people live with dementia, and this number is projected to increase to 152 million by 2050. The increasing numbers of people with dementia, has a great and increasing social and economic impact. EDA Leaders, adult educators who provide training about dementia and other stakeholders have to focus on reducing modifiable risk factors for dementia. The WHO Guidelines are an important tool for health care providers, EDA Leaders, adult educators, public entities and other stakeholders to strengthen their response to the dementia challenge.

(Source: World Health Organization. (2019). Risk reduction of cognitive decline and dementia: WHO guidelines.)

Effective Policies On Adult Lifelong Learning And Education

Education was recognized internationally for the first time as a human right in the 1948 Universal Declaration of Human Rights (UDHR) which states in Article 26 that 'Everyone has the right to education'. According to the United Nations' Committee on Economic, Social and Cultural Rights (CESCR), the right to education "epitomizes the indivisibility and interdependence of all human rights" (CESCR, 1999, General Comment No. 11: Plans of Action for Primary Education, Doc. E/C.12/1999/4).

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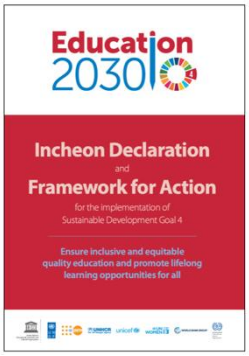

To know more:

The SDG 4-Education 2030 Framework for Action was adopted in order to ensure inclusive, equal and quality education and promote Lifelong learning. It outlines how to translate into practice, at country/national, regional and global level, recommendations and principles. It aims at mobilizing all countries and partners around stainable Development Goal (SDG) on education and its *targets, and proposes ways of implementing, coordinating, financing and* monitoring Education 2030. It also proposes indicative strategies which countries may wish to draw upon in developing contextualized plans and strategies, taking into account different national realities, capacities and levels of development and respecting national policies and priorities.

(Source: Sachs-Israel, M. (2016). The SDG 4-education 2030 agenda and its framework for action–the process of its development and first steps in taking it forward. Bildung und Erziehung, 69(3), 269-290.)

A Methodological Focus on Adult Learning

Adult lifelong learning about dementia is the way to push the topic of dementia closer to the lives of the entire citizenry and not just to those living with a diagnosis and those who are caregivers. It is the tool in order to address social exclusion and supporting care providers and caregivers giving voice to people with dementia and promoting dementia inclusive communities and initiatives.

As reported in United Nations Educational, Scientific and Cultural Organization Guidelines to strengthen the right to education in national frameworks (2021), in order to implement and coordinate education and Adult lifelong learning according to State obligations, a step-by-step **Methodology** can be followed:

1. **Data collection**: analyze the general country context and collect information on the current status of the right to education at national level.
2. **Data analysis**: use evidence and data as a basis for comparison and analysis, assess and evaluate areas of compliance or gaps between national and international educational policy to draw conclusions to ensure a better alignment with these benchmarks.
3. **Formulate recommendations**: basing on data analysis collected to inform legal and policy elaboration and reform for the full realization of the right to education and to advance
4. **Implement recommendations**: basing on identified gaps recommendations should be wrote in order to support, strengthen and implement rights-based, inclusive policies and strategies.

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Following UNESCO Methodology 2021, "MYH4D Recommendations for EDA leaders" present:

1. **Dementia collection of information/good practices** to inspire supportive community integration and inclusion and to improve quality of life of people living with dementia, their caregivers and families, a participative process is essential.

2. **Methodological nudges** to support compliance and participative policy, as involving civil society, trade unions, staff associations, education institution leaders, teachers and students (both private and public sector) as well as parents and families in developing strategies and initiatives. The diversity and plurality are important to ensure engagement and inclusive participation.

3. **Recommendations to EDA Leaders** to support local self-help groups, community-based activities and improve participation of people living with dementia in decisions that affect them and in events involving citizenship.

4. **Filling the gaps**: Fostering curiosity and openness to the most effective policies to compare them with those in one's own context. Especially endorsing the circulation of information for mutual learning from existing policies.

To know more:

For EDA methods to support community health literacy about dementia, policy good practices please see MYH4D Be connected MOOC (2022).

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Chapter 1 – The Power of Inclusion and Integration

***Responsible partner**: ASL TO3 (IT)*

The chapter in brief: *To support community integration and inclusion means fill the gap between people living with dementia and their caregivers and community. Fighting the stigma toward dementia is an increasing public social* priority.

1.1 Inclusion and Integration: a public social priority

There is an increasing acknowledgement as a public social priority of dementia, the related stigma and the need to implement strategies to support inclusion and integration.

What policy makers should remind:

- Ageing is not only about vulnerability and dependence, older people become more wise and trusting, they are able to maintain social engagement in the community, dignity and independence.
- People living with dementia are not their diagnosis, they are individuals with a history, personality, relationships and desires
- Diagnosis of dementia does not the define every aspect of life, nor does it mean that life is over
- For people living with dementia, full and equitable engagement in everyday life activities as well as social inclusion is often possible

A Focus on Dementia related stigma

Definition

According to Link and Phelan, 2004 dementia related stigma can be conceptualised as:
"the co-occurrence of its components: labelling, stereotyping, separation, status loss, and [...] emotional responses [...] (Link and Phelan, 2004). Due to cultural beliefs about aetiology and antisocial behaviours, the diagnosis of dementia carries significant stigma leading to stereotyping of all people with dementia. People is more reluctant to talk about it, resulting in a delay in diagnosis and low priority given to dementia care services. This has a great impact on:

- welfare
- mental health
- physical health of individuals
- maintaining social hierarchies

EDA Leaders and adult educators should advocate the importance and the nature of measures to contrast stigmatisation and support inclusion and integration

1.2 Addressing Dementia Related Stigma

Why is important to reduce stigma? To promote timely diagnosis, more appropriate care and quality of life of people with dementia. A few points of attention for Adult Educator (EDA) leaders are:

- **People living with dementia maintain many habits** they used to have, as maintaining the ability to receive, access and understand health information
- **Symptoms change over time**, but complex functionality (e.g. cooking, gardening, singing, playing…) can be maintained throughout the course of the disease.
- **There are many activities** (e.g. travelling, volunteering, walking and practicing physical activities) which can be adapted to allow the person to participate in social activities

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3 Tips to Support Integration and Inclusion

1. Promote a better education about dementia, provide knowledge, skills and competences encouraging people to find innovative solutions, improve personal resources, cultivate their own social and emotional life
2. Provide a safe, supportive environment with high levels of dignity and respect
3. Keep in mind the uniqueness of each person, seen as a sentient being with important resources and an emotional life that needs to be recognised and supported

1.3 Advocacy for Public Actions: designing policy to improve adult education

EDA leaders have to inspire new knowledge, skills and competences inside the society in order to support community integration and inclusion. Stigma needs to be addressed not only by challenging the personal beliefs, but also aspects of society that emphasise the separateness of people with dementia.

3 Pillars for effective policies and initiatives

I Positive language and reframing approach. To know more, click here

II People with dementia's active participation in advocacy activities

III Integrative policy approach

In the following paragraphs EDA leaders will find different nudges to take into account. An example of each policy will be provided as "Good practice".

1.4 Dementia prevention policies

Policies and strategies for dementia prevention have to address the full range of dementia-specific factors including social isolation and lack of cognitive stimulation. They include:

- Promoting awareness of resources that provide general public with information about the risk factors for dementia and the actions they can take to reduce their risk
- Mitigating identified modifiable risk factors, improving access to education and countering risk factors. Integrate and scale-up interventions that enable behaviour focusing on modifiable risk and protective factors for dementia
- Improving the quality and availability of care. Coupling the seek for cure with urgent investment in primary prevention measure

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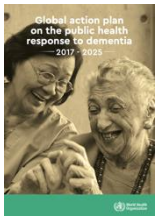


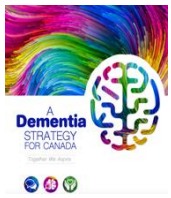
Good practice

The Global action plan on the public health response to dementia 2017-2025 is a good example of prevention policies is provided by the Global action plan on the public health response to dementia 2017-2025. Full text of the plan is available here

1.5 Integrated policies

EDA Leaders should work for the creation of an integrated dementia network and management. This means:

- **Ensuring clear and easy to access** information and available services to facilitate access. Promoting awareness of resources about dementia, ensuring that every network has general information available
- **Making care homogeneous**, paying attention to social inequalities and health care fragilities. Promoting prevention, early diagnosis, favouring appropriate intersectoral policies. Ensuring that dementia networks work in accordance with the dementia care standard and person-centred approach.
- **Training health and social care staff** providing them with the right skills, knowledge, behaviours and values to support people living with dementia
- **Improving quality of life** and care and promoting full social integration. Building community resilience, creating opportunities for people with dementia to make the most of their remaining capabilities, in accordance with their personal wishes. Providing opportunities for doing work, including volunteer activities, for example in DemenTalent projects



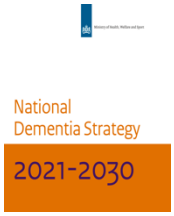
Good practice

The Dementia Strategy for Canada 2019 aims at integrating health equity into government policies and programs to enable equal access to dementia supports. For more information click here

1.6 Shared and participative policies

It is essential to involve people with dementia, their carers and families in developing policies and plans to enhance collaboration with care providers. EDA Leaders should:

- Remind that people living with dementia are the experts about what it's like to live with dementia
- Promote all forms of participation, through the involvement of families and associations, developing not only the empowerment of individuals but also that of the community
- Support community integration and inclusion as engaging, auditing and involving directly people living with dementia in dementia tables, in the planning and facilitation of activities
- Ensure person-centred support and gender-sensitive, culturally appropriate care. Shift care from hospitals to multidisciplinary, community- based settings
- Provide information to empower people with dementia to make informed choices about their care.



Good practice

The Dutch National Dementia Plan 2021-2030 aims at providing care enhancement and creating dementia friendly society. More information about the plan is available here

1.7 Verified and measured policies

A cause of the significant impact on the welfare and costs, policies need to be evidence-based, cost-effective, sustainable and affordable, and take public health principles and cultural aspects into account. To accomplish this EDA Leaders should:

- **Foster access to best available research**, and data compatible with local conditions, to ensure full participation of local communities.
- **Identify knowledge, and technical support needs** and gather evidence (including experiences of those living with dementia and caregivers)
- **Take into account both quantitative** (e.g., epidemiological) and qualitative data (e.g., narrative accounts). Use surveys of best practices to collect valuable information
- **Identify measurement tools and indicators** (process, content and outcomes indicators), apply evaluative criteria to assess interventions and outcomes
- **Communicate data effectively**, using existing analytic tools, conducting policy surveillance and tracking outcomes with different types of evidence
- **Support partnerships**, multi-sector alliances and mutual cooperation with stakeholders, institutions, scientific community and local universities. Enhance trans-disciplinarity and participatory processes

Good practice

The National Plan to Address Alzheimer's Disease: 2021 Update offers an overview of strategies and programs based on research evidence. For more information about the plan click here

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Chapter 2 - Lifelong e-learning for older people

***Responsible partner**: Foundation Compassion Alzheimer Bulgaria (BG)*

The chapter in brief: *The Chapter introduces the main characteristics of lifelong learning and e-learning for older people, the benefits for the educational leaders and illustrates good practices in this field.*

2.1 What is lifelong learning for older people

For European societies ageing is one of the greatest social and economic challenges and it will affect nearly all EU policy domains. Institutions that teach older people need to address learning content through different methodologies and to create specially designed courses, activities and materials. **The main aim of lifelong learning for this group is to increase learners' well-being and quality of life**.

Why Lifelong Learning Is So Important For Older People

Cognitively stimulating activities like reading, watching documentaries and getting out exploring the world around you offers the following cognitive health benefits:

- **It enables older people to gain self-confidence, demonstrate creativity, and share their skills and experience.** The moral support provided reduces the risk of social exclusion, achieving mutual understanding between the generations.

- Older age offers the chance for gaining from new opportunities because people generally have more time to participate in social activities. Lifelong learning can be done with the others! Learning courses, discussion groups and book clubs can spark social interaction that is intellectually engaging and **helps avoiding depression and isolation.**

- **Increased Neuron Generation**. Lifelong learning has been found to stimulate greater neuron generation and connection in the brain.

- **Reduced Risk of Forms of Dementia**. This greater neuron generation can maintain and enhance brain health. Activities like learning a new language and mastering a new gardening technique are cognitively stimulating and may reduce the risk of Alzheimer's disease and other forms of dementia.

- **Improved Ability to Handle Challenges**. Simply reading a book or practicing an instrument can decrease muscle tension and blood pressure. Lower stress levels can help for better coping with challenging situations and changes in life.

Education is essential in the realisation and protection of the rights of older people and clarifying the responsibilities, taking responsibility for their own destiny. **Older people require knowledge, competence for healthcare and longevity, skills for daily activities, hobbies, social work, attendance to peer and youth on preservation of intergenerational relations**.[1] They should participate in the design of the education process and a continuous feedback gathering system is needed in order to collect ideas and preferences from them.

2.2 Benefits for EDA leaders and qualities that they should develop

- There is empirical support for the effectiveness of e-learning environments structurally arranged in specific ways (instructional interactions, systems, tasks and texts). As a result, learning processes are facilitated, encouraging older people to engage and persist in learning activities.
- Merrill's 5 principles of instruction are related to the following elements: 1) Problem-orientation: learners deal with issues of real life; 2) Activation: prior knowledge of learners is used to activate new knowledge; 3) Demonstration: new knowledge is shown to learners; 4) Application: new knowledge or skills are used to solve a problem; 5) Integration: learners use new knowledge or skills in their real life.
- According to Harvard Medical School, while learning patterns may change and the speed of learning may diminish, the basic capacity to learn remains. Stimulating new social connections with others and social activities, e.g. dance class, book club, digital photography helps the brain staying active and may improve cognitive health. Many NGOs, colleges and universities have designed ongoing education programs for ageing people who want to learn

Teaching is also a socio-educational activity where more formal, non-formal and informal activities are being used. The knowledge students acquire is important, but other skills, attitudes and aims should not be forgotten such as socialisation, integration, adapting to society, active citizenship, etc. **The role of the people and institutions who design the programs should have strong focus on motivating the learners**.

2.3 How to make Adult lifelong e-learning happen. Good practices

Among older people the most common reasons for motivation to learn are: to find out about a subject they are curious about; to know more about today's society and its history; to understand modern society and be updated with changes; to avoid exclusion; and to remain active and creative. Successful ageing is not only a disease-free life but also requires subjective life satisfaction, social participation, good cognitive performance and psychological resources.

Knowledge can be accessible as well via the Internet and the media and thanks to specialized agencies for older students. In the UK, those are "Open universities" and University of the "third age" (U3A), in the United States: education institutions for people of retirement age and boarding houses for retired (Elderhostel), in Germany: Academy for the elderly (Seniorenakademien) and public schools (Volksschulen) (Vyssotskaya, & Mitina, 2010).

Below are some examples of good practices. The coaches should have the proper professional qualifications for their implementation:

- Lectures and seminars from different subjects could be offered and those that are most positively valued by the learners could be repeated periodically. At the same time new subjects are offered.
- A reminiscence group supports the psychological wellbeing of a person and is usually a natural part of ageing where a person relives his/her life.
- A peer support group that has its individual focus, e.g. on sharing feelings of widowhood or loneliness.

Through e-learning and new technologies the learning can become more effective and reach more people. For example, through the use of cloud technologies, tablets, smartphones, visiting virtual communities. Lifelong learning for older people should be accessible, with free access and assistance should be provided to

those who lack e-learning skills. All generations should be educated about specific topics as intergenerational dialogue and dementia. Young generation can participate in the support and education of older people.

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Chapter 3 - Adult lifelong learning and communication

***Responsible partner**: ZDUS (SI)*

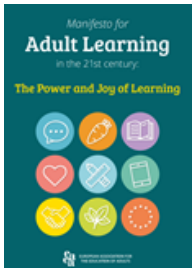
The chapter in brief: *The chapter offers an insight on the importance of adult lifelong learning about dementia, giving adult educators elementary advice on how to prepare and deliver trainings about dementia to support and empower communities living with dementia.*

3.1 Advocating the Importance of Learning about Dementia

It's a common known fact that lifelong learning has the potential to improve people's lives and is a starting point for changing perceptions and narratives about dementia in communities. Adult educators play a crucial role in advocating the importance of learning about dementia outside formal education and not only for healthcare professionals, but for members of an entire community. Lifelong learning is the empowerment tool for addressing social invisibility and exclusion of people living with dementia, supporting carers in giving voice to people with dementia and promoting dementia inclusive communities and initiatives. Increased knowledge and understanding of dementia by people within the community can start changes that enable people with dementia to live well as long as possible.

Therefore adult educators who provide training about dementia in the communities should:

- Step outside the »traditional teaching mind-set« and focus on teaching in non-formal environments,
- Prepare meaningful and engaging teaching to motivate learners,
- Pay special attention to language and images used in teaching materials,
- Show examples of dementia inclusive communities and raise awareness



*"**The health of our societies depends upon lifelong learning**," says the Manifesto for Adult Learning in the 21st century: The Power and Joy of Learning, highlighting the importance of (non-formal) adult education.*
In matters of health and well-being adult educators are the ones that carry out important tasks in encouraging participation of learners and communities. This can be done by reaching out for non-formal methods and methodologies, adapting to learner's needs and giving them essentials skills to manage their health issues

The MYH4D Community of Practice offers the opportunity for adult educators to get involved in discussions with other adult educators and share experiences on these topics.

3.2 Getting Closer to the Community

Adult lifelong learning about dementia should happen in non-formal community spaces. These can play an important role in reaching and motivating learners to participate. Dementia still bears negative connotations and learners may be reluctant to take part in trainings that are organised in formal settings such as health care centres and mental health institutes for example

Adult educators should:

- Do initial research and get to know their target learners. For example: attending local festivals and community events can be beneficial for preparing targeted teaching.
- Search for non-formal environments, public spaces that have established relationships within the community and are concerned with later-life issues. For example: a reading club for older people might be interested in debating about a book telling somebody's life-story about dementia.
- Find out which local media are active and use established community services to reach out to potential learners. For example: a local store owner can put up a poster of a training in his store.
- Break the barrier of not discussing mental health issues in communities by including local people who have experience with dementia as spokespersons.

"If people were more understanding of dementia then they would treat people with dementia better."[4]

This statement is from one of the findings of a UK study, conducted on behalf of the IDEAL programme team, which explored what could be changed in the local community to enable those with dementia to live well. Participants of the study, people with dementia and their informal carers, identified that **education and training about dementia in communities** would bring greater social awareness and understanding, which would enable them to access activities and support services and engage in social contact.
The full study is published here.

3.3 Making Learning about Dementia Engaging

Teaching practices on dementia topics should be tailored to the needs of the learners. Experiences of adult educators who provide training to informal carers and people with dementia show that communities need capacity and experience-based learning to gain skills and competences that will impact and improve their everyday life.

Adult educators should:

- Have in mind that there are different types of learners and that learning objectives and learning outcomes will differ based on their role in dementia care.
- Target the needs of learners, be responsive and use individualised teaching approaches, ensuring that learning will be relevant and usable in people's lives.
- Use methods and tools that are interactive. According to Edgar Dale's Pyramid of Learning people learn best when they are actively involved in the learning process. For example: don't start your training with mentioning 10 warning signs of dementia, but engage learners in an activity with which they will indirectly learn about them.
- Don't lecture, but create opportunities for people to open up and share their problems and experience of living with dementia. Let them have their say.

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"Include discussion, group work, practical activities, experiential exercises, simulation, realistic scenarios, viewing videos, talks by carers and people with dementia, multimedia on-line content …"[5]

An extensive overview of "What Works"[6] in dementia training is provided in the study done by the Center for Dementia Research with National Institute for Health Research UK. Researchers identified effective approaches that bring the best outcomes when it comes to dementia education and training in terms of the impact on gained knowledge and changed attitudes for people with dementia and their carers.
Full manual on designing dementia training is available here.

3.4 The Power of Positive Language and Images

Teaching materials shape our knowledge and they influence how a learner internalises the information that is being presented. That is why teaching materials about dementia need to promote inclusive practices, break misperceptions about dementia and challenge ageism and stigma. Proper language and visuals (photo material) about dementia can empower and raise awareness about the importance of respectful communication.

Adult educators should:

- Be committed in preparing teaching materials that use and promote positive language about dementia. Words empower people and can change how society views people with dementia.
- Pay special attention in using proper visuals in teaching materials: images or photos. Although using visuals helps with comprehension, visual ageism about dementia is still strongly embedded and present in the media, showing disabilities of people living with dementia rather than their abilities.

GOOD PRACTICE
Dementia Diaries is a UK project, a website that offers a series of video and audio stories from people with dementia, documenting their lives and experiences. It provides a deeper understanding of why positive language matters to people with dementia and gives insight into public perceptions they're faced with.

3.5 Empowerment changes in the community

Changes for people living with dementia and their carers start in communities where they live. Teaching about dementia in communities should include active learning or learning by example, as this increases learners' understanding of dementia and encourages critical thinking. Learning about possible solutions that work and impact people whose lives are touched by dementia can lead to changes and greater engagement of the community.

Adult educators should:

- Show-case examples of dementia inclusive societies to broaden horizons of learners and show what can be done to improve the quality of lives of people with dementia and their caregivers.

- Search for dementia friendly initiatives and stories, involve them to promote positive experiences in the community. Remember communities can learn from each other.

GOOD PRACTICE

There are many dementia friendly and inclusive initiatives to share. They do not have to be large-scale, involving big structures and a lot of resources. Adult educators should promote feasible initiatives that could also be done in the communities where they teach.

Such is a good practice example of "Lenny the mobile barber", the first dementia friendly barber for nursing homes in Northern Ireland: https://lennythedementiafriendlybarber.com/

Additional learning resources for adult educators can be found at the MYH4D Be connected MOOC which offers teaching methods and proposes activities for delivering training regarding dementia literacy.

3.6 References

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Conclusion

***Responsible partner**: Zorg Kortrijk (BE)*

The conclusion in brief: EDA leaders contribute to fight the stigma, to increase lifelong learning and to empower community

As stated by the WHO and Alzheimer's Disease International (2012) dementia is a public health priority worldwide. The contribution of Eda leaders can make a difference. How?
MYH4D recommendations indicate:

- why adult education about dementia is important and what knowledge increase community health literacy
- how adult educators can support and improve a more competent and sensible community towards people with dementia and their caregivers

Knowledge about dementia focuses on 2 pillars:

- **Prevention**: can we prevent dementia? Studies show that up to 40% of the incidence of dementia can be prevented. A healthy lifestyle and access to primary health care are the 2 basic concepts. A healthy lifestyle means paying attention to the physical, cognitive, social and spiritual life. This both on an individual level and on a societal level. Access to primary healthcare means that health problems known to be risk factors for dementia (e.g. high blood pressure, depression, hearing impairment, etc.) can be recognized and treated.
- **Diagnosis and management**: increasing the knowledge about dementia ensures that both diagnosis and guidance of people with dementia can be done with respect of the person as a member of society. In this way, education about dementia is not only important for caregivers but for everyone. Lifelong learning about dementia could be the way to bring the topic of dementia closer to the lives of the entire population and not just those directly involved

Recommendation 1: Fighting stigma

EDA leaders have a crucial role to frame stigma and provide skills and knowledge to counter it by:

- increasing knowledge, skills and competence about dementia
- giving a voice to people with dementia, reinforcing their active role into the community
- talking differently about dementia, using positive language and re-framing agism

We can reduce stigma, making people with dementia and their carers feel that they belong in society and that their experiences are taken seriously! EDA leaders contribute to gathering and sharing knowledge, skills and good practices with each other. This in ways that are respectful, cost-effective, evidence-based, sustainable and take into account public health principles and cultural aspects.

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To know more about stigma, see Chapter 1:

The first chapter dealt with the stigma that still rests on Dementia. Stigma is when someone views you in a negative way because you have a distinguishing characteristic or personal trait that's thought to be, or actually is, a disadvantage (a negative stereotype). Unfortunately, negative attitudes and beliefs towards people who have a mental health condition are common. In this way, through the self-fulfilling prophecy, people with dementia can get the feeling that they are not of value, that they are a burden to society. This also has an influence on the informal caregivers who make their story known less and less. Because of the stigma, people are less likely to proceed to diagnosis and assistance. In this way, the isolation of people with dementia and their informal carers increases even more.

Recommendation 2: Increasing Lifelong Learning

Lifelong learning is important for acquiring knowledge and learning new skills. **It also helps increase self-confidence and in older age it reduces exclusion from society.**
In addition to traditional education, e-learning offers new opportunities. Especially in light of the past Corona crisis, where contacts were reduced. Sharing knowledge, sharing good practices becomes easier by e.g. cloud technologies, tablets, virtual communities. An interactive programme increases involvement of different stakeholders.

To know more about stigma, see Chapter 2:

The advantages of E-learning are:

- flexible
- cost-saving
- time-saving
- customized learning
- more fun learning
- overview of achievements
- more interaction
- comfortable

Recommendation 3: Addressing the empowerment of the community through lifelong learning

Lifelong learning is one of the empowerment tools to achieve a dementia-friendly, inclusive society.
Therefore, it is indispensable for adult educators to know the community they teach for. That way, they can bring knowledge about dementia in an engaging and community-appropriate way.
The chapter provided concrete tips and external links to adapt their lessons to the target audience and knowledge-sharing content. It is also important to pay attention to positive language, images and shared examples of dementia-inclusive communities. Which raise awareness along so that people with dementia, their carers feel accepted in the community.

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To know more about Lifelong learning, see Chapter 3:

The final chapter gave more insight into the importance about lifelong learning about dementia. it also gave advice to adult educators on how to prepare and deliver lessons/trainings. Adult educators have an crucial role in advocating lifelong learning about dementia. This not only to care workers or informal carers but to everyone in society**.**

A call to action for EDA leader:

Education or knowledge sharing is an important tool to tackle social exclusion and to support people with dementia and their caregivers. E-learning programs contribute to this by sharing knowledge, good practices and mutual interaction.

To know more about inclusive community and the contribute of Adult Educators see:

The European Erasmus+ Programme MYH4D Mooc 'Be Connected' give adult educators opportunities to adapt their lessons on dementia. Whereby the MYH4D Community of Practice offers the opportunity to exchange knowledge and experiences.

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Afterword 1 - Ethical analysis

***Responsible partner**: Instituto Etica Clinica Francisco Valles (ES)*

The chapter in brief: *MYH4D Recommendations for Adult Education leaders are inspired by the capability approach (CA). CA is a normative framework to assess individual well-being and the circumstances influencing people's quality of life. The main idea of that theory is to consider the preferences and wishes of a person involved in decision-making and his agency and freedom.*

Capability approach in dementia care

MYH4D Recommendations for Adult Education leaders are inspired by the capability approach (CA). CA has already been used in healthcare for research focusing on person-centred care, people with dementia living self-sufficiently, the dignity of patients with advanced dementia and relatives of people affected by dementia who make decisions according to what patients voiced before the illness. CA is a normative framework to assess individual well-being and the circumstances influencing people's quality of life. The main idea of that theory is to consider the preferences and wishes of a person involved in decision-making and his agency and freedom. CA values two fundamental aspects: the distinction between the *promotion of agency goals*, which a person is determined to achieve according to his idea of well-being, and the difference between their achievement and the *freedom to achieve such goals*. The idea of capabilities put at the centre of decision-making what a person wishes to do and be and the freedom to attain such being and to do. The CA can help to understand the encounter between informal carers and people with dementia and explore how the different stages of dementia and next-of-kin coping strategies might improve respect for freedom and patients' wishes. Consequently, thinking in terms of capabilities provides comfort to persons with dementia who have the possibility to make their decisions according to what they can do. Carers and relatives of people with dementia respond to the challenges produced by the everyday life care of the person with a plurality of strategies justified by different reasons. The capability theory is valuable to explore how carers maintain their decisions to support autonomous choices in spite of the progressive person's cognitive impairment. The role played by carers and families lifestyle choices, cultural background, feelings and beliefs or their interpretation of "how the patient was before the illness" are all crucial in determining the capabilities of people with dementia because guide decision-making related to all course of action available. The quality of care for people with intellectual disabilities relies on their capabilities, and informal carers influence how these are converted in functioning. The Art 12 of the UN Convention on the Rights of Persons with Disabilities (CRPD) (2006) defined legal capacity as a universal human right that cannot be undermined for any physical or mental disability. Despite the controversial acceptance of CRPD, the main message vehiculated is the need to support people with mental disabilities with measures oriented to respect their human rights, will and preferences. The difference between capacity and incapacity in people with dementia represents a big challenge for formal and informal carers who struggle to consider their loved ones' opinions when they represent a risk for themselves or others. In dementia, capacity is progressively changing without a standard pattern, and the available tools for its assessment are tailored to a dichotomic model for which a patient has or not capacity. Blurred capacity is a frequent condition in people with dementia, especially in the early stage of the disease. On one hand, the lack of an effective tool to distinguish the degree of capacity in dementia requires an alternative approach to paying attention to the need for respect for the human rights of people with intellectual disabilities, as stated in the CRPD recommendation. On the other hand, the progressive cognitive impairment produced by the disease requires best interest decisions to promote the health of people with dementia. CA approach helps carers to find an alternative to this binary model of capacity and may help them to be concerned about how the freedom and wishes of their loved ones can be promoted and respected, despite their disability.

Afterword 2 - MYH4D Methods

***Responsible partner**: Instituto Etica Clinica Francisco Valles (ES)*

The chapter in brief: *The consortium of Move your hands for Dementia (MYH4D) developed digital content following two main methodological approaches: Agile methodology and the capabilities approach. Both methods represented only a reference to advise the research team in developing the three intellectual outputs according to the needs of the target groups involved in our research activities.*

A methodological note about MYH4D contents provided into the Intellectual Output (MOOC, Community of Practice and Recommendations).

The consortium of *Move your hands for Dementia* (MYH4D) developed digital content following two main methodological approaches: the Agile methodology and the capabilities approach. Both methods represented only a reference to advise the research team in developing the three intellectual outputs according to the needs of the target groups involved in our research activities. The real-world focus of MYH4D aims to influence the work of trainers and informal carers through evidence-based practice. In doing this, we have structured our work into two phases: a generation phase inspired by the systematised review of scientific literature and qualitative research, which explored stakeholders' views with fifty in-depth interviews carried out in all the countries involved in the consortium. By the correlation between literature and individual experiences of dementia care, we have established a relationship between the circumstances of the illness and how they are experienced individually by people involved in formal and informal care. The strategy devised by researchers to design and develop the MYH4D's digital artefacts was assessed by a group of representatives of the target groups who assessed their feasibility during the entire course of the project. An evaluation phase located at the end of the production of each intellectual output estimated the quality of the single digital product. In the former, we ensured that all the designed contents were tailored to the learner's needs and in the latter, we explored how successful the artefact was perceived. The second methodological approach helped researchers to define a framework, whose clinical, social and ethical aspects were aligned and theoretically informed. The contingency faced by informal carers and the next-of-kin of people with dementia required an assessment of their welfare from a double perspective: the well-being achieved and the possible well-being achievable in the future. The British economist and philosopher Amartya Sen defined the former as something measured by functioning and capabilities. The progressive evolution of dementia demands a strategy to deal with present circumstances and plan a future passed by the deterioration of patients' quality of life. Martha Nussbaum, an American philosopher who owes Sen's theory a great inspiration, defined the capability approach as focused on "what people can be and do". That is why the capability approach represented a reference to the design of several of our MOOC's content and community of practice.

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