

Move your hands for dementia - ZDUS involved in an Erasmus+ project

Age member from Slovenia, ZDUS, has a diverse membership, amongst which are many older people who volunteer in the ZDUS social-care programme *Older people for better quality of living at home*. The purpose of the programme is to visit peers, older people in their community and provide or organize the help they might need. Among the older people that need assistance are also people with dementia, their carers or family members who still live in their own home in these conditions. ZDUS volunteers are trained for such voluntary work on an annual basis. The trainings are conducted by their peers, adult educators. The educational network, which in such an important program runs from adult educators to volunteers and users, is a unique process in which we must ensure that all actors have the appropriate competencies to achieve the ultimate goal, which is a better quality of life of older people in need.

Therefore, it was very natural for ZDUS to respond to the invitation of the Italian health institution AslTo3 from Turin, which came up with the idea for the European project *Move your Hands for Dementia* (MYH4D), which ZDUS will implement in the next two years in collaboration with partners, health professionals, education and NGO sectors from Italy, Belgium, Bulgaria, Cyprus, Greece and Spain. We will focus on community health literacy about dementia, because it enables to approach problems in this area with more responsibility and can, with more knowledge and competencies on the matter, improve the quality of life of people with dementia and their carers in the community.

The project, which primarily supports adult educators in strengthening their competences in education on the topic of health literacy on dementia, will also focus on other target groups, which we consider key in creating a more inclusive and equal, dementia-friendly community. These are people with dementia, family and informal carers, education leaders and policy makers. The project will create a massive open online course "Be Connected" for adult educators, implement two community practices for adult educators and people with dementia and their family members, and publish a guide with guidelines for improving sustainable education strategies and policies related to dementia.

What have informal carers of people with dementia had to say on their dementia care experiences?

"I tell you from my own experience; it's hard to take care of someone 24 hours a day. What can I tell you, this is life." These are the words of a 66-years old informal carer from Ajdovščina (Slovenia) who took care of her mother-in-law who was a person with dementia and was receiving care at her home.

Such and other similar were confessions and stories from Slovenian informal carers of people with dementia which ZDUS collected in March for the European project *Move your hands for dementia*. ZDUS completed a series of 10 interviews with informal carers of persons with dementia and with

Project Number: 2020-1-IT02-KA204-079434

volunteers in caring for a person with dementia. The fact that all interviewees were women is not surprising at all, as we are aware that the vast majority of carers in EU are women and that overall women commit more time to caregiving than men. Our interviews revealed that in most cases these informal carers were caring for a family member with dementia and some for their neighbours in the community. The majority said that they could perform such care duties because they were already retired, with more time and that if they were still in their active working period, this would not be possible. The carers also emphasized that everybody who is in care contacts with older people should know more about dementia, have more skills to recognize the first signs and have more practical knowledge on how to conduct a conversation with a person with dementia. Some carers said that the worst part is when family members, acquaintances and friends move away from the person with dementia, stop visiting them because of their own fear from the unknown and because they simply don't know how to approach a person with dementia, their old friend.

»At her house they simply wouldn't accept that she was developing dementia.« /.../ suddenly or step by step everything was changing, disappearing. And it's hard to accept it and I feel there is certain pain within the family ... and on the other side there is that acceptance of your own helplessness that you actual can't help the person (with dementia). I think that accepting dementia is a big problem.» These are the findings of informal carers who say that families embrace change with their loved ones in different ways. They believe relatives, caregivers and all those involved in caring for people with dementia need to be helped to cope and accept the situation, and empowered with other people's experiences and ways to improve the lives of both people with dementia and their own lives as carers: *"You know the hardest part is when people and families start to hide that somebody has dementia, because they feel embarrassed ... This is hard to deal with,"* they stated. But the project Move your hands for dementia believes dementia health literacy and building on communication skills for example can make a difference: *"I found out that if you are nice to the person (with dementia), if you don't deny what they are saying and you try to talk to them in words they follow and seem to understand ... this is the way to go. /.../ Carers of people with dementia often forget that such people forget things, but their emotions are still deep within them. Maybe they don't know how to talk the right way anymore, maybe he doesn't know or recognize things anymore, but his feelings are still there. So, we need to treat them with care, talking nicely, slow and easy and in many times a touch can do wonders."*

These words of a 82-year old informal carer from Ptuj (Slovenia) who took care of her husband with dementia should make us think that as a society we should not withdraw from people with dementia, on the contrary, we should try to make them live a quality life as long as possible by visiting them and supporting all those who care for them, you would be surprised what amazing life energy these carers have, as we found out in our interviews.

For more information on the project, please visit:

The project website: <https://myh4d.pixel-online.org/index.php>

Project Facebook page: [MYH4D European Project](#)

On behalf of the *Move your hands for dementia* project team
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