Visions for the Future of Dementia Friendly Communities: Workshop Report

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1 Introduction and background

Dementia Friendly Communities (DFCs) represent a change in the approach to the way societies think about dementia. The diagnosis and management of dementia have traditionally been defined by the medical model. A more holistic approach developed in recent years places the person with dementia within the context of their community. The concept of a DFC therefore emerged as a community where people with dementia are respected and involved; recognising and addressing some of the challenges people face, but also providing opportunities for people with dementia to engage with their communities and valuing the contribution they can make to society.

The concept of DFCs has spread around the world to encompass a wide range of activities. The first Dementia Friendly Community projects were developed in Japan, but soon spread through European countries and the Americas. The concept has been adapted and defined in different ways for a diverse range of settings. However, fundamental common elements include training ‘dementia friends’, providing services that are adapted to people with dementia, and facilitating opportunities to participate in communal activities.

Despite the widespread adoption of DFCs, many questions remain about their future direction:

- Should local, national or international priorities direct the form of DFCs?
- What are the best ways to achieve a DFC?
- What role can young people play in shaping their own communities to become dementia friendly?

As WYLD we believe that, alongside other stakeholders, the voices of young people should be heard in shaping the future direction of DFCs. Many young people are affected by dementia as family members, but also have
specific roles within their communities that bring them into close and regular contact with people with dementia. Firstly, young people make up a substantial proportion of those providing voluntary services. Secondly, there are a growing number of young professionals working in the field of dementia as advocates, carers, health professionals, artists and in other roles. This unique and diverse body of young people has an important role to play in the future of DFCs.

In order to consider how best to hear and involve young people in DFCs, we organised a workshop on Visions on the Future of Dementia Friendly Communities at the 27th Alzheimer Europe Conference, Berlin, October 2017. The theme for the conference was “Care today, cure tomorrow” and brought together close to 750 participants from 42 countries, including 181 speakers and 216 poster presenters.

The World Young Leaders in Dementia workshop attracted around 40 delegates from a range of ages and professional backgrounds. The workshop was divided into two parts: firstly presentations from experts in the field (including members of the World Young Leaders network), secondly a period of discussion to generate ideas on the future of DFCs to be taken forward in the World Young Leaders in Dementia’s future work in this area.

2 Speaker presentations

To set the scene for later discussions we asked three speakers to introduce the concept of DFCs as they applied to the international field (Ana Diaz, Alzheimer Europe), the national context (Olivier Constant, WYLD) and local projects (Verena Tatzer, WYLD). These talks were followed by a period of discussion around three issues:

- Visions for the future of DFCs
- Examples of good practice for DFCs
- The role of young people in DFCs

DFCs across Europe

Ana Diaz (Alzheimer Europe) provided a global insight in the development of the DFC concept in Europe, based around a comparative study conducted in 2015. The report demonstrated the work of several countries in Europe where the concept of DFC’s is in the process of becoming part of the everyday lives of people with dementia, but also that the development of DFC’s happens at different speed, levels and scope in different regions. Building on the ‘age-friendly framework’ developed by the World Health Organisation, the study provides information about national policies and practices that aim to create inclusive physical environments, transportation, businesses, leisure activities and services that are part of the day-to-day life of most citizens. Key aspects of this work towards becoming dementia friendly include tackling the stigma of dementia and promoting a greater involvement of people with dementia in society.

DFCs at a national level

To convey the implementation of DFCs at a national level, Olivier Constant (WYLD/Flanders Centre of Expertise on Dementia) presented the Flemish vision and practice on awareness raising and DFCs, inspired by the Flemish Dementia Strategy and scientific research. The new Dementia Strategy in Flanders emphasises emancipatory communication with and about people with dementia as the starting point for DFCs.

Olivier addressed the social construction of dementia, discussing the narrative encouraged by the media that people with dementia are dependent, isolated and weak. He presented the Flemish government’s approach to oppose this message with the campaign ‘Forget dementia, remember the person’. He also presented the new ‘dementia friendly proof meter’ together with a movie on dementia friendly communities in Flanders.

All the Flemish dementia friendly projects have a common goal: putting empowerment of people with dementia into practice and giving back their dreams, quality of life and remaining capacities.

DFCs at a local level

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Presenting an example of a local project embedded in the DFC framework, Verena Tatzler (WYLD/Fachhochschule Wiener Neustadt) presented a pilot project on the ‘Friendly Community Pharmacy’. People living with dementia and their caregivers are regular users of community pharmacy services which is an easily accessible and local healthcare setting. Resource-orientation, aiming at participation and empowerment of all actors are basic principles in this approach that foster dignity, quality of life and reduction of stigma. The pilot project showed that successful reorientation of health services is possible through using a participatory research approach to improve interface-settings for people with dementia and their caregivers. The pharmacies participated in series of workshops on communication, networking with local providers and pharmaceutical care in order to further develop knowledge in dementia care. Subsequently, through ‘practice-based projects’ developed by community pharmacies, interventions in the community setting were tested.

Community pharmacies are important health care providers for caregivers, offering not only advice on medication, but also on local support organizations and psycho-social support. In this way pharmacies are also a crucial actor in enhancing resilience of informal caregivers and detecting caregiving burden. This may be especially important in rural areas where specialized services are rare and information is scarce. Networking in the wider community is a prerequisite for success. The Dementia Friendly Pharmacy is an innovative approach with the potential to inspire other related projects and manages to build bridges between a medical approach and psycho-social support and inclusion.

3 Discussions

Following the presentations, the workshop split into discussion groups that took the form of a ‘world cafe’. In this setting there were three topics, each discussed around a single large sheet of paper. Workshop participants wrote down their thoughts, adding to or expanding on those of previous discussants. The three topics were:

- Visions for the future of DFCs
- Examples of best practice
- How can young people contribute to DFCs?

3.1 Visions for the future of DFCs

The two main themes to emerge from the discussion on visions for dementia friendly communities were those of: 1. Inclusion, 2. Implicit dementia friendly societies.

Comments about inclusion were the most popular to be written down, eg "Everyone included", "warm society with a place for everybody”. Many comments cited roles both for people with dementia and members of the community. For example, people with dementia should take on "Active citizenship", and be "Active as co-researchers". For the community, comments centered around organisations, eg "Commerce, seniors, gov’t and attitudes allow for families with dementia to access all that exists for participation in society", "Activating society is a hell of a job but starts with people who are involved! Not only do training etc but how to keep up every organisations: banks, shops, sports clubs, neighbourhood". The latter comment highlights the difficulty of changing deep-seated societal norms.

A strong theme in comments about inclusion was partnership between people with dementia and other members of society, for example "collaborate and achieve more together", "My vision is a community where everyone feels included, where everyone feels free and able to enjoy life!".

The second most common theme was building a society where dementia friendly characteristics are implicit rather than having to be an explicitly stated aim:

- "Vision = Dream = Community where dementia doesn’t matter \(\rightarrow\) from dementia friendly to caring community"
- "My vision is that there will be no need for ‘DFC’ as every community will already be dementia friendly"
• “My vision is a society where we all live together without the need to label "DFC" because we will naturally be inclusive without any discrimination and stigma”

3.2 Examples of best practice

One of the most best received and most discussed suggestions in this group was the involvement of people with dementia via a ‘think tank’. This enables people with dementia to set the agenda and priorities for DFCs.

Many suggestions related to facilitating people with dementia access to participate in leisure and cultural activities. These included: arts organisations, museums, cinemas, libraries, therapeutic gardens, walking groups, football clubs. Other suggestions focused on community amenities, including: pharmacies, banks.

A couple of best practice examples focused on breaking down barriers between school children and people with dementia: “Training in schools”, “Reduce stigma by reaching out to school children to understand ‘dementia’ and by ‘educating’”.

A few suggestions addressed nursing homes and staff training: “Nursing home training”, “Importance of communication between management of the lead training home and local authorities to work on a DFC → win-win”. The second of these comments place nursing homes at the heart of a broader dementia friendly community.

3.3 Suggestions for young people

The main theme that emerged during discussions about the role of young people in dementia friendly communities was young people as advocates:

• “Share their experiences of being affected by dementia”
• “Bring home knowledge and messages to their parents”
• “Be ambassadors for DFC and contribute to understanding (frail older people cannot do it)”
• “Lobbying for non-medical/psychosocial interventions”
• “Start with local meetings between younger people through youth organizations to generate enthusiasm and a call to action to involve them in building a DFC.”

Other comments highlighted:

• Specific skills and knowledge of young people that may be relevant to people with dementia, “Teach people with dementia and their carers to use technology”, “Use their knowledge to provide answer to actual challenges in dementia care”
• Sustainable, mutually beneficial, intergenerational projects: “Students living in care homes”, “Be a buddy, do things together, learn from each other...”, “Build further on intergenerational projects. Not as ‘one shots’, but as a structural added value in dementia care and the community.”
• Involving school children “Get young people (secondary school) through volunteering get involved in activities with PWD. But students need to be educated about dementia first”
4 Outcomes of the workshop

During the workshop delegates from all over Europe not only brainstormed and discussed their priorities for the dementia-friendly community of the future, they also presented their personal vision through photographed visual statements. After the workshop, these were turned into a dementia-friendly video statement, which will be made internationally available through our website and online channels. Moreover, this workshop report and a conference report are available through the WYLD website.

This report is a next step in the ongoing WYLD-work on DFC’s, which has recently become a major theme for the network over to develop over the next 2 years. We wish to inspire ongoing projects at a local level to learn from ‘good practices’, identify opportunities and difficulties in the creation of DFC’s and facilitate different platforms to exchange practical and research based knowledge.

As WYLD we see these outcomes from the workshop as a ‘work in progress’ and as a new reference point to move forward on dementia-friendly communities within and outside Europe. Therefore we will work further on innovative and transnational initiatives and communication to translate this message in the different knowledge and practice fields of our members: policy, research, daily care practice, communication.

5 Conclusions

- The discussion of DFCs should begin with people with dementia, potentially in a think tank
- Societies should move towards implicit dementia friendliness
- Young people are potential advocates for dementia friendly communities
- Societal change through school children may be a route towards more dementia friendly communities of the future
- DFCs should help people with dementia to enjoy life and participate in society