



EFN POSITION PAPER ON DEMENTIA CARE

Dementia is one of the major healthcare challenges for Europe and a key priority for the 2015-2016 Luxemburg and Dutch EU Presidencies. Across the world, an estimated 44 million people now live with dementia; this number is set to double by 2030 and triple by 2050¹. Dementia is one of the most debilitating conditions in modern society with huge health, social and financial implications². People's lives, families and communities can be disrupted from the onset of dementia, while dementia is also increasingly considered as one of the leading causes of death among older adults. The direct financial cost of dementia to the European Union (EU) is estimated to be in excess of €130 billion a year³.

While substantial, these figures considerably underestimate the scale of the issue because dementia continues to remain under-diagnosed in the EU⁴. Considering the increasing and substantial impact of dementia on EU citizens and society, there is an urgent requirement for a coordinated and comprehensive approach at EU level whereby all relevant actors – including civil society, policy makers, industry, academia – work together to manage the burden of dementia and promote relevant interventions and pathways that increase the safety and quality of life of those living with dementia, their families and carers. Coordination at European level is paramount if the EU is to respond to this challenge collectively.

Nurses are in the unique and privileged position of having direct access to the daily care needs of people with dementia, and have a key role to play both in managing and preventing this condition. Nurses are the ones best placed to ensure practice, knowledge and research develop in response to and in conjunction with people's needs, and that this gets translated and implemented into the daily practice of professionals. A great contribution can be made in key areas such as care coordination, quality of care in hospitals and other residential settings, as well as implementing and evaluating evidence of best practice at local level where it counts which will improve the quality of care and life for people living with dementia, as well as their families and carers.

However, in order to be able to provide this appropriate care for people with dementia and their family carers, there is a need to have in place different priorities, strategies, structures and the recognition and acknowledgement of nurses' role in caring for people with dementia.

Therefore, the EFN calls on the Commission, European Parliament, Council, Health Stakeholders, and the Member States to:

- Coordinate and collaborate between all relevant health and social, professional and policy actors towards developing and implementing a meaningful and concrete strategic list of priorities for tackling the dementia challenge at EU level;
- Develop strategies that deal with dementia holistically, focussing on prevention, risk assessment and risk reduction, as well as on the provision of quality care for people with dementia and their families. There is substantial evidence indicating that the risk of developing dementia can be modified through a healthier lifestyle⁵;
- Recognise and involve nurses in the development and deployment of dementia strategies and policies at EU and local level, making best use of the collective knowledge and experience of the profession from caring for people with dementia, their relatives and carers;
- Recognise and increase nurses' role and activities in early identification, prevention and health promotion; and its importance within inter-professional collaboration. Nurses have a key role in public health and prevention in particular, due to their unique insight of the patient experience and familiarity with people's social and family contexts. This enables them to form a comprehensive assessment and discuss targeted interventions with people that can be directly applied to individual circumstances. Identifying and supporting

patients and family carer needs, identifying risk factors and potential hospitalisations and collaborating within multidisciplinary teams;

- Invest in the education and training of nurses, especially in advance nurse practitioners, in preparation for adopting a greater role in the management and care of people living with dementia, and of their families, to include assessment and care planning, early diagnosis⁶, care coordination and evidence-based decision making. Nurses can provide input from a holistic assessment to the wider healthcare professional team, having an oversight of the care plan, ensure there are timely referral to special services, and then coordinating the discharge process with community services. That process reflects a bio-psycho-social approach to care management;
- Prioritise continuity and integrated care to coordinate care for people with dementia across health and social care settings. eHealth solutions shall be integrated into daily practice and people's lives in a way that encourages independent monitoring and care management, thus empowering and increasing individuals' control⁷; and,
- Use Horizon 2020 to pace up the scale and scope of research on dementia in Europe, particularly through addressing dementia as a societal and health challenge. There is scope for work on understanding the determinants, risk factors and pathways of diseases like dementia, as well as comparing the effectiveness of best practices and health interventions for the older population, developing guidelines for dementia care and exploring eHealth approaches to self-management. Furthermore, it should be further explored how the development and use of big data can contribute to advance dementia research⁸.

The 6 million nurses deployed across 34 countries in Europe, represented through the European Federation of Nurses Associations (EFN), are ideally placed to help the EU respond and contain the dementia challenge from the level of day-to-day practice, where people with dementia face the difficulties of daily life. Nurses are the ones best placed to ensure practice, knowledge and research develop in response to and in conjunction with people's needs; and that this gets translated and implemented into the daily practice of professionals towards improving the quality of care and life for people living with dementia, as well as their families and carers.

References:

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