



Informal Meeting of Health Ministers

24-25 September 2015, Luxembourg

Session I:

Supporting people living with dementia: Improving care policies and practices

Discussion paper

The burden of dementia in today's societies

Today more than six million people are living with dementia, which makes this disease one of the biggest health challenges in the European Union. Among older people dementia is one of the major causes of disability and dependency worldwide. It has physical, psychological, social and economic impact on patients, their families and caregivers as well as on society.¹

Addressing dementia becomes a necessity not only in the interest of the persons directly affected but also to ensure the sustainability of health and social systems. The demographic change of an ageing European population will be an enormous challenge in terms of costs for health and social security systems.

Most Member States find it difficult to pool the existing knowledge about evidence-based interventions and research findings and to make use of it in everyday practice in the fields of health and social care. Better access to relevant information and its integration into policies and practices would create benefits for patients, their related persons, health and social care professionals as well as for decision makers.

The Luxembourg Presidency would like to invite Ministers to discuss priorities of future collaboration among Member States and the need of further action on EU level, where there is added value. A particular focus will be put on timely diagnosis and post-diagnostic support to make secondary prevention of dementia most effective.

Member State's responsibility to act

Over the last years, more and more Member States are attaching high priority to dementia, conscious of their primary responsibility to act. Initiatives in place or under way in an increasing number of Member States are based on an integrated approach to the patient pathway considering health and societal issues².



The Luxembourg Government adopted in 2013 a national action plan on dementia³ focusing further actions on seven priorities including prevention, diagnosis and treatment. Different implementing measures have been adopted, of which most recently a multidimensional secondary prevention programme (pdp) for people with dementia at an early stage, launched on 29 June 2015 by the Ministry of Health.

The overall aim of this programme, providing post-diagnostic support for people with dementia at an early stage, is to maintain the quality of life of affected persons and their relatives, by preventing the onset or delaying the progression of the disease and to enable persons to stay in their home environment as long as possible. By pursuing a patient-centred and patient-driven approach, rather than an approach where the role of the patient is passive given that he receives support from family and carers, the pdp sets the ground for an important paradigm shift in dementia care.

Luxembourg's experiences with pdp might be of interest to other Member States and qualify, once evaluated, as good practice example.

Ministers are invited to share their experiences to allow for an overview on dementia policies in Member States and to reflect on common ground for further action.

Dementia initiatives at EU level

The Presidency furthermore encourages Ministers to discuss the added value of closer cooperation and coordination at EU level in the field of dementia.

Since the French Presidency Council Conclusions in 2008 on public health strategies to combat neurodegenerative diseases associated with ageing calling on the Commission to adopt an initiative in 2009 to combat these diseases, numerous initiatives at EU level have acknowledged dementia as a priority for action in the context of demographic ageing (see overview in Annex). They have highlighted the important consequences of the increase of these diseases for the financial sustainability of health and social protection systems and have identified areas for further action.

Coordination of national research, identification and dissemination of good practices and funding of research projects have thus been promoted. As a result, more than half of the Member States have adopted either national dementia strategies or plans.

The Group of Governmental Experts on Dementia, created in February 2014, aims at further promoting exchange of good practices and experiences as well as enhanced coordination between Member States as regards their public health activities in the field of dementia.

Most recently, the Italian Presidency suggested specific further action and invited Member States to continue addressing dementia as a core issue in their policies. It was also suggested to the Commission to consider changing the status of the Group of Governmental Experts on Dementia into a formal EU-Expert Group which should be a forum for exchange, cooperation and coordination between Member States. The Commission and Member States have been



encouraged to bring forward the second Joint Action on Dementia, and the future Presidencies of the EU to make dementia part of their Presidency Programmes.⁴

As member of the current Trio-Presidency, the Luxembourg Presidency keeps dementia on the political agenda as one of its public health priorities and the incoming Dutch Presidency will continue this work within the new Trio with Slovakia and Malta.

Dementia initiatives at international level

Health Ministers are invited to also keep in mind the ambitious initiatives that have been brought forward by the World Health Organisation (WHO) and the Organisation for Economic Co-operation and Development (OECD) as well as by the G8 Health Ministers at the Summit on 11 December 2013 under the G8 Presidency of the United Kingdom.

The results of these initiatives have been reflected and further developed at the first Ministerial Conference on Global Action Against Dementia held in Geneva in March 2015⁵, supported by the OECD and the Department of Health of the United Kingdom. Participants expressed their wish to wave the multiple new initiatives into a comprehensive plan for coordinated global and national action by signing a Global Call for Action. They furthermore emphasized the need for a Global Dementia Observatory to ensure health service planning based on accurate scientific evidence and public health needs through a mechanism for continuous monitoring of action on dementia.

Against this overall background, the Luxembourg Presidency would like to invite Health Ministers to discuss the following questions:

Question 1: Is dementia a public health priority in your country and, if so, by what measures is it addressed?

Question 2: How can prevention, timely diagnosis and post-diagnostic support contribute to the reduction of the burden of dementia?

Question 3: How can EU level cooperation – through formal cooperation of Member States in the EU Governmental Expert Group on Dementia and through stronger coordination with relevant WHO initiatives – facilitate sharing of good practices and how can it support countries to develop and implement national dementia strategies / plans?

Question 4: Is there added value to discuss an EU strategy in the field of dementia and, if so, which aspects should be covered?



ANNEX

Dementia initiatives at EU level:

- *Council Conclusions* on public health strategies to combat neurodegenerative diseases associated with ageing and in particular Alzheimer's disease adopted at the EPSCO Council on 16 December 2008⁶
- *Communication from the Commission* COM(2009) 380/4 to the European Parliament and the Council on a European initiative on Alzheimer's disease and other dementias⁷
- *Joint Action ALCOVE*⁸ carried out under the leadership of France under the second Health Work Programme (2008-2013) addressing questions such as improved data collection for better knowledge about dementia prevalence as well as improved and timely access to dementia diagnosis; a second Joint Action is planned under the lead of Scotland on behalf of the United Kingdom financed by the third EU Health Programme (2014-2020)⁹ with the aim to focus notably on diagnostic and post-diagnostic support, crisis and care pathways, improving the quality of residential care, and dementia-friendly communities
- *European Innovation Partnership on Active and Healthy Ageing* (2012-2015) is targeting prevention of cognitive decline and development of age-friendly environments and EU research policy¹⁰
- *7th Framework Programme for Research and Technological Development* (2007-2013) spent more than 555 million Euros in funding on research into dementia and neurodegenerative diseases between 2007 and 2013. Building on these results, the new *EU Framework for Research and Innovation – Horizon 2020* will allow to further address dementia as a societal and health challenge¹¹
- *Innovative Medicines Initiative*, jointly funded by the European Union and the European pharmaceutical industry association (EFPIA) offers additional funding for Alzheimer research¹²
- *Joint Programming Initiative on Neurodegenerative Diseases* (JPND) adopted in 2008 is aiming at better coordination of research efforts¹³
- *Resolution of the European Parliament* on a European initiative on Alzheimer's disease and other dementias is calling for dementia to be made an EU health priority and urging Member States to develop dedicated national plans¹⁴



Dementia initiatives at international level:

- The *First report on Dementia of WHO* in 2012 provided information and raised awareness of dementia and made dementia one of the priority conditions in the WHO Mental Health Gap Action Programme (mhGAP), which aims to scale up care for mental, neurological and substance use disorders¹⁵
- *Declaration of G8-Health Ministers on Dementia* adopted on 11 December 2013 at the G8 Summit, to foster innovation, to identify a cure or a disease-modifying therapy for dementia by 2025 as well as strategic priority areas and to increase funding of dementia research¹⁶
- *OECD report* on “better dementia care and a future cure require action today” from 13 March 2015, reaffirming the necessity for political prioritisation of dementia¹⁷.



¹ WHO, Fact sheet N°362, March 2015.

² See overview at <http://www.alzheimer-europe.org/Publications/Dementia-in-Europe-magazines> .

³ See <http://www.sante.public.lu/publications/rester-bonne-sante/sante-mentale/plan-action-national-maladies-dementielles/plan-action-national-maladies-dementielles.pdf> .

⁴ Conclusions of the Presidency Conference “Dementia in Europe: a challenge for our common future”, held in Rome on 14th November 2014 and co-organised and financed with the European Commission, for download at <http://www.salute.gov.it/portale/ItaliaUE2014/dettaglioEvento.jsp?lingua=english&id=246> .

⁵ See <http://www.who.int/mediacentre/events/meetings/2015/global-action-against-dementia/en/> .

⁶ See http://www.consilium.europa.eu/ueDocs/cms_Data/docs/pressData/en/lsa/104778.pdf .

⁷ See http://ec.europa.eu/health/archive/ph_information/dissemination/documents/com2009_380_en.pdf .

⁸ See overview on initiatives in staff working document on the implementation of the Commission Communication on a European initiative on Alzheimer's disease and other dementias, SWD(2014) 321 final of 16.10.2014.

⁹ Regulation (EU) No 282/2014 of the European Parliament and of the Council of 11 March 2014 on the establishment of a third Programme for the Union's action in the field of health (2014-2020) and repealing Decision No 1350/2007/EC.

¹⁰ See http://ec.europa.eu/health/ageing/innovation/index_en.htm .

¹¹ See overview in the Commission's implementation report on the Commission Communication on a European initiative on Alzheimer's disease and other dementias, Commission Staff Working Document, SWD(2014) 321 final, 16.10.2014, p. 11 and following.

¹² See www.imi.europa.eu .

¹³ See <http://www.neurodegenerationresearch.eu/> .

¹⁴ Doc. (2010/2084 (INI), 19 January 2011.

¹⁵ See http://www.who.int/mental_health/mhgap/en/ .

¹⁶ For download at <https://www.gov.uk/government/publications/g8-dementia-summit-agreements> .

¹⁷ See <http://www.oecd.org/newsroom/better-dementia-care-and-a-future-cure-require-action-today.htm> .