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OUTCOME OF PROCEEDINGS

From: General Secretariat of the Council

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To: Delegations

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Subject: Supporting people living with dementia: improving care policies and practices

– Council conclusions (7 December 2015)

Delegations will find in the annex the Council conclusions on supporting people living with dementia: improving care policies and practices, adopted by the Council at its 3434th meeting held on 7 December 2015.

**Council conclusions
on supporting people living with dementia:
improving care policies and practices**

THE COUNCIL OF THE EUROPEAN UNION

1. RECALLS that under Article 168 of the Treaty on the Functioning of the European Union a high level of human health protection must be ensured in the definition and implementation of all Union policies and activities, and that Union action, which is to complement national policies, is to be directed towards improving public health. The Union is to encourage cooperation between Member States in the area of public health and, if necessary, lend support to their actions and foster cooperation with competent international organisations. Union action must fully respect the responsibilities of the Member States for the organisation and delivery of health services and medical care, including allocation of the resources assigned to them;
2. NOTES WITH CONCERN that 47.5 million people worldwide are currently living with dementia, 58 % of which live in low- and middle-income countries. It is estimated that in the European Union 6.4 million people live with dementia¹;
3. RECALLS that dementia is one of the major causes of disability and dependency among older people worldwide and that it has a physical, psychological, social and economic impact on people living with dementia and on their families and caregivers, as well as on society²;

¹ WHO, Fact sheet No 362, March 2015, <http://www.who.int/mediacentre/factsheets/fs362/en/>; ALCOVE Joint Action report, Executive Summary, p. 29, http://www.alcove-project.eu/images/synthesis-report/ALCOVE_SYNTHESIS_REPORT_WP4.pdf.

² WHO, Fact sheet No 362, March 2015.

4. RECALLS that while the majority of people with dementia are elderly, there are also a significant number of people with early onset dementia;
5. EMPHASISES patients' rights, particularly those related to human dignity, as laid down in the EU Charter of Fundamental Rights³;
6. RECOGNISES that people can live well with dementia for a number of years, in particular if timely access, assessment, diagnosis and the right support are in place;
7. RECOGNISES the significant impact of dementia and of diseases linked to dementia on the financial sustainability of health and social security systems;
8. EMPHASISES the importance of promoting healthy lifestyles, including for brain health, throughout the life cycle, in order to increase healthy life years;
9. RECALLS that a better understanding of these conditions is required to achieve high health standards for an ageing society, which is one of the priorities of both the second and the current third Health Programme (2014-2020)⁴;
10. RECALLS that numerous initiatives at EU level have also acknowledged dementia as a priority for action in the context of demographic change and reiterated the significant consequences of the increase in the number of people living with the disease⁵;

³ See Chapter I on Dignity, available to download at http://www.europarl.europa.eu/charter/pdf/text_en.pdf.

⁴ 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); OJ 21.3.2014, L86/1

⁵ See overview on initiatives in the field of dementia – such as the ALCOVE Joint Action, the European Innovation Partnership on Active and Healthy Ageing, the European Pact for Mental Health and Well-Being, the European platform to facilitate proof-of-concept for prevention of Alzheimer's Disease (EPOC-AD) and the Innovative Medicines Initiative – contained in the 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.

11. RECALLS the Council Conclusions adopted on 16 December 2008 on public health strategies to combat neurodegenerative diseases associated with ageing, which called on the Commission to adopt an initiative in 2009 to combat these diseases⁶;
12. RECALLS that the Commission proposed a new approach for making better use of Europe's public R&D funds through Joint Programming in key areas that include Alzheimer's disease. As a result, the Member-States led Joint Programming Initiative on Neurodegenerative Diseases (JPND) was launched in 2010 with the aim to better coordinate national research efforts in the field of neurodegenerative diseases and in particular Alzheimer's disease;
13. RECALLS that the 7th Framework Programme for Research and Technological Development (2007-2013) spent more than EUR 576 million in funding on research on dementia and neurodegenerative diseases between 2007 and 2013; building on these results, Horizon 2020 (2014-2020), the new EU Framework for Research and Innovation – Horizon 2020 allows to further address dementia as a societal and health challenge, with already more than EUR 103 million invested in dementia-relevant research and innovation actions;
14. WELCOMES the Resolution of the European Parliament, adopted on 19 January 2011, on a European initiative on Alzheimer's disease and other dementias calling for dementia to be made an EU health priority and strongly urging Member States to develop dedicated national plans⁷;
15. RECALLS the first report of the World Health Organisation (WHO), 'Dementia: A Public Health Priority'⁸, published in 2012, which provided information on and raised awareness of dementia and made it one of the priority conditions addressed in the WHO Mental Health Gap Action Programme⁹, which aims to scale up care for mental, neurological and substance abuse disorders;

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

⁷ 2010/2084 (INI).

⁸ WHO, 'Dementia: a public health priority', 2012, available to download at

http://www.who.int/mental_health/publications/dementia_report_2012/en/.

⁹ http://www.who.int/mental_health/mhgap/en/.

16. WELCOMES the 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 for research¹⁰;
17. RECALLS the Italian Presidency Conference 'Dementia in Europe: a challenge for our common future', held in Rome on 14 November 2014¹¹, which provided an overview of initiatives on dementia in the EU, notably on prevention, treatment and elderly health promotion;
18. RECALLS the report of the Organisation for Economic Cooperation and Development (OECD) of 13 March 2015 entitled 'Better dementia care and a future cure require action today'¹², which reaffirmed the need for dementia to be made a political priority;
19. WELCOMES the Call for Action signed by participants at the first WHO Ministerial Conference on Global Action Against Dementia in Geneva on 17 March 2015, which underlined governments' primary role and responsibility in responding to the challenge of dementia and emphasised the need for multi-sectoral and coordinated action at global and national level, aimed notably at advancing prevention, risk reduction, diagnosis and treatment of dementia¹³;
20. STRESSES that in recent years dementia has become a high priority for more and more Member States, given the fact that development, adoption or implementation of national strategies, action plans or programmes addressing dementia are ongoing in the majority of the Member States; that Member States' initiatives already in place or under way are based on an integrated approach to the patient pathway which considers health and social issues;

¹⁰ <https://www.gov.uk/government/publications/g8-dementia-summit-agreements>.

¹¹ <http://www.salute.gov.it/portale/ItaliaUE2014/dettaglioEvento.jsp?lingua=english&id=246>.

¹² <http://www.oecd.org/newsroom/better-dementia-care-and-a-future-cure-require-action-today.htm>.

¹³ <http://www.who.int/mediacentre/news/releases/2015/action-on-dementia/en/#>.

21. WELCOMES the discussion at the informal meeting of EU Health Ministers on 24 September 2015 on fostering development and implementation of national strategies, action plans or programmes on dementia as well as on facilitating the exchange of best practices at EU level, taking into account WHO activities;
22. WELCOMES the second Joint Action on Dementia, to be launched in 2016.

INVITES THE MEMBER STATES TO:

23. ADDRESS dementia as a priority through cross-sectoral national strategies, action plans or programmes on dementia to provide appropriate treatment and assistance to people living with dementia, their families and caregivers, while ensuring the sustainability of health and social security systems.
24. CONTINUE to devote special attention to strengthening the coordination within Member States of relevant policies in the field of dementia, including reinforcing the role of primary care.

INVITES THE MEMBER STATES AND THE COMMISSION TO:

25. RECOGNISE that continued collaboration across sectors among Member States and at EU level – taking into account WHO activities – will allow for a valuable contribution to improve the support of people living with dementia;
26. RECOGNISE the benefits of the empowerment of people living with dementia and encourage their inclusion in decision-making processes by strengthening their representation, particularly in initiatives, organisations and bodies in the field of dementia;
27. SUPPORT a gender-sensitive, individual-and research based approach in the elaboration of strategies, plans and programmes on dementia, taking account of groups with specific needs, the impact of cultural diversity on perceptions of dementia, as well as the expectations and rights of people living with dementia and their families and caregivers;

28. RECOGNISE the important role of families and caregivers, notably by ensuring their inclusion in decision making processes, and the need to protect their physical and mental wellbeing through adequate support.
29. ACKNOWLEDGE the important work of the Governmental Expert Group on Dementia in facilitating the sharing of experiences and good practices to support Member States in developing and implementing national strategies, plans or programmes on dementia;
30. SUPPORT work in the context of EU policy areas that might have an impact on dementia policy, notably the Working Party on Public Health at Senior Level as well as the Social Protection Committee (SPC)¹⁴ and the Economic Policy Committee (EPC)¹⁵ on health care and long-term care;
31. TAKE FORWARD, while fully respecting Member States' competences, discussions at EU level on the following issues:
 - a) the role of prevention and health promotion, risk reduction, early detection, timely diagnosis and post-diagnostic support in contributing to the reduction of the burden of dementia;
 - b) ways of ensuring that prevention, diagnosis, treatment and care is coordinated within countries, involving multidisciplinary expertise, and that it is delivered closer to home;
 - c) the added value of the exchange of best practices with a focus on key components and tools to ensure the quality of care of patients and the support of carers, in order to better assess the various approaches and practices in these areas;
 - d) the promotion of the rights of people living with dementia, with a particular focus on the ethical dimension of dementia in order to ensure healthy ageing in dignity;
 - e) the use of the potential of eHealth and assistive technologies in improving support and care for people living with dementia;

¹⁴ SPC Working Group on Ageing Issues, see <http://ec.europa.eu/social/main.jsp?catId=758>.

¹⁵ EPC Working Group on Ageing Populations and Sustainability,
http://europa.eu/epc/working_groups/ageing_en.htm.

- f) the pooling of and access to existing knowledge about ongoing initiatives and the related evidence base as well as its integration into everyday practice in health and social care;
 - g) the need to promote the role and continuing education of health professionals to ensure the best possible support for people living with dementia and their families;
 - h) the promotion of dementia-friendly communities;
32. INTENSIFY research on dementia, building upon the result of EU funded projects such as EU Joint Programming Initiative on Neurodegenerative Disease (JPND), particularly on its risk factors and underlying pathophysiology, as well as translation of successful interventions on dementia management into clinical practice, also considering public-public, public-private and international partnerships;
33. BENEFIT from resources, models and tools successfully developed at EU level, such as those gathered by the European Innovation Partnership on Active and Healthy Ageing, the ALCOVE Joint Action and from the strategies developed for scaling-up good practices;
34. DEVELOP, where appropriate, in close cooperation with the Governmental Expert Group on Dementia, voluntary guidance based on a comprehensive and integrated perspective on dementia, taking into account the aspects of coordinated prevention and health promotion, timely diagnosis, post-diagnostic support, treatment and care, while respecting Member States' competences;
35. IDENTIFY and EXCHANGE, in close cooperation with the Governmental Expert Group on Dementia, good practices, notably as regards targeted prevention, including secondary prevention, health promotion, timely diagnosis, post-diagnostic support and therapy, research, training and further education of health professionals, as well as public information to combat stigma;
36. IMPROVE the quality of epidemiological information on dementia to facilitate the development of national strategies, actions plans or programmes as well as the exchange of good practices;

37. EMPHASISE the work of non-governmental organisations and voluntary work in the field of dementia aiming to contribute effectively to national strategies, action plans or programmes.

INVITES THE COMMISSION TO:

38. STRENGTHEN the cooperation of Member States in the Governmental Expert Group on Dementia to facilitate the sharing of information on policy frameworks and of good practices already in place, as well as to support countries in developing and implementing national strategies, plans and programmes on dementia;
39. FOSTER the ongoing cooperation with the WHO and the OECD on dementia, in close coordination with Member States.
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