



Declassified<sup>1</sup>  
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## Committee on Social Affairs, Health and Sustainable Development

### Minutes

#### of the hearing on “The provision of palliative care in Europe” held in Strasbourg, on Wednesday, 24 January 2018, from 2.45 to 3.30 pm

The Committee **held** a hearing with the participation of:

- Mr Philip Larkin, Professor of Clinical Nursing (Palliative Care), University College Dublin and Our Lady's Hospice and Care Services;
- Ms Tiina Saarto, Professor of Palliative Medicine, Chief Physician, Palliative Care Center, Comprehensive Cancer Center, Helsinki University Hospital, Helsinki University;
- Mr Henri de Rohan-Chabot, Executive director, *Fondation France Répit*.

**The Chairperson** opened the hearing and welcomed the experts.

**Mr Larkin** explained that the understanding of palliative care had progressed over the years. The WHO definition included elements such as the need for an “interdisciplinary approach”, the objective of improving the patient’s “quality of life” and treating not only pain but also other problems, “physical, psychological and spiritual”. It was also widely acknowledged now that palliative care did not only concern older or dying persons, but a range of patients with long-term conditions. In Europe, palliative care provision had a significant financial and organisational impact on health and social systems. Mr Larkin recalled that access to palliative care was a human right. Integrating palliative care into the health and social care systems and ensuring well-coordinated service provision by different providers were crucial to adequately support patients with palliative care needs and their families, as well as to reduce costs linked with excessive hospitalisation of these patients.

**Ms Saarto** noted that political leadership was essential to stimulate the integration of palliative care into the health care systems and the development of quality care provision. National legislations and regulations were needed to set up standards for resource allocation, impose educational requirements for palliative care provision, as well as to define types of care settings where palliative care could be provided. Recalling that access to palliative care was a human right, Ms Saarto stressed the symbolic and practical importance of the upcoming Assembly Resolution on this issue, which would not only constitute a strong European voice for the provision of palliative care, but also help countries to set up relevant standards.

**Mr de Rohan-Chabot** stressed that informal caregivers (i.e. mostly family members) played a crucial role in the provision of palliative care. That role was expected to further increase against the background of an ageing population and longer lives as a result of medical developments. Home care services were oriented towards the patient without due consideration of the needs of informal caregivers, whose lives were greatly impacted at all levels (professional, social and family life) as a result of their caring activity. It was essential to provide support for informal caregivers, including by taking measures to offer them respite. *France Répit* Foundation’s main objective was to offer this possibility to patients’ families. A pilot project offering different services to patients’ families, including a “respite house” was currently being conducted in Lyon, and co-financed by different authorities, including the State. A dignified home care until the end of life could not be delivered without proper support to informal caregivers.

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<sup>1</sup>Minutes approved and declassified by the Committee on Social Affairs, Health and Sustainable Development at its meeting on 20 March 2018 in Paris.

*The experts' Power Point presentations are available on the PACE Extranet linked to this hearing.*

**The Chairperson** thanked the experts, in particular for stressing the difficulties encountered by families. The situation of informal caregivers was no different in Austria where many of them were children aged 14 to 18. A recent law had recognised informal caregivers' right to an annual holiday. In some countries, similar laws were also allowing the possibility to take a sabbatical leave, reduce working time and receive financial support.

**Ms Mergen** congratulated the experts for the quality of their interventions. She recalled that in the past, the debate around palliative care concentrated mostly on the issue of "therapeutic obstinacy" and respite for patients. She stressed that early diagnosis, integration of palliative care in general medicine, and coordination between different care providers were crucial in ensuring quality palliative care. In Luxembourg, relatives who provided care were protected against the financial losses resulting from a reduction of their working hours via a special insurance scheme.

**Baroness Massey** asked if and how faith-based organisations, such as hospices, were cooperating with different palliative care providers and what were the sources for funding palliative care provision. She also wondered to what extent countries invested into public awareness-raising and professional training for palliative care.

**Lord Touhig** acknowledged the importance of providing respite services to informal caregivers. However, he wondered how this could effectively be implemented against the background of a constant reduction in health budgets. Charities could maybe play a role in supporting this cause.

**Mr Amraoui** noted that there were many patients living in geographical zones far away from a hospital and palliative care services. In Morocco, there were five to six respite houses, called "*maisons de vie*". It would be important to integrate those respite services into the healthcare system, instead of making them dependent on charities.

**Mr de Rohan-Chabot** said that integrating respite services into the health care system would not necessarily lead to an exponential increase in costs. In fact, the excessive use of emergency services, a recurrent problem in the context of palliative care provision, was much more costly. He thought that spending did not always match the real needs of patients and that palliative care services could be improved without extensive investment.

**Ms Saarto** thought that basic palliative care provision should be publicly financed and could be supported by NGOs. Referring to the comment on the problem of access to care in rural areas, she said that every country had to find the best adapted solution to this problem. She also underlined the importance of providing palliative care education for health care professionals who often lacked basic knowledge in this field.

**Mr Larkin** stressed that most hospices were originally created by faith-based organisations. In the provision of palliative care both the voluntary sector and the general health care system should work together for the best outcome. Cultural aspects and values should be taken into account in the provision of palliative care.

**Mr Mullen**, the Rapporteur, thanked the experts and members for their contributions. He stressed that palliative care provision was much broader than simply providing services; it was about respect for human rights and dignity.

**Ms Mergen** pointed out that good palliative care provision was a good remedy against euthanasia.

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**Commission des questions sociales, de la santé et du développement durable**  
**(81sièges)**

**List of presence / Liste de présence**

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Mr / M. Henri de Rohan-Chabot, Executive director, *Fondation France Répit / Directeur exécutif, Fondation France Répit ;*

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Ms / Mme Marina Davidashvili, Senior Policy Officer, EPF – European Parliamentary Forum on Population and Development / *Le Forum parlementaire européen;*

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