

European Association for Palliative Care

EAPC Onlus: Non profit-making Association
Non Governamental Organisation (NGO) recognised by the Council of Europe
Association Européenne pour les Soins Palliatifs

EAPC Onlus: Organisation à but non lucratifs d'utilité publique ONG reconnue par le Conseil de l'Europe

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Task Force Proposal Form

Formulaire pour propositions pour des groupes de projets

Information about applicant /coordinator - Information sur le proposant /coordinateur

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Information about project – Information sur le projet

1) Project title Titre projet	Palliative Care in Long-Term Care Settings for Older People	
2) Objectives Objectives	 The aim of this taskforce is to identify and map the different ways of developing palliative care in long term care settings. In order to do this we will address the following objectives: To define long term care settings for older peopel and the nature of palliative care in these settings To identify practice development initiatives being undertaken to develop and impact on the provision of palliative care in long term care settings for older people (including action research, transdisciplinary and intervention research approaches within organisational development). To map palliative care initiatives in long term care settings for older people across different countries To create a compendium of good practice interventions in relation to palliative/end of life care in long term care settings for older people 	

3) Members of group (names, titles, addresses)

Membres du groupe (noms, titres, addresses..) We have identifed the following structure for the taskforce. We will establish a core working group who will be supported by an advisory group and then a wider network of people who will be kept informed, and consulted when information is required.

Core working group

Dr Katherine Froggatt, International Observatory of End of Life Care, Lancaster University, Lancaster, **UK***

Dr Elisabeth Reitinger, IFF-Palliative Care and Organisational Ethics, University of Klagenfurt, Vienna, **Austria***

Dr Katharina Heimerl, IFF-Palliative Care and Organisational Ethics, University of Klagenfurt, Vienna, **Austria**

Dr Jo Hockley, St Christopher's Hospice, London, UK

Prof Kevin Brazil, McMaster University, Hamilton, Canada

Dr. Roland Kunz, Palliative Geriatrics, Hospital Affoltern, Switzerland

Associate Prof Deborah Parker, University of Queensland, Brisbane, Australia

Dr. Bettina Sandgathe-Husebø, Department of Public Health and Primary Health Care, Kavli's Research Center for Dementia, University of Bergen, **Norway**

Advisory Group

Sigrid Beyer, Hospice Austria

Mary Bower, Irish Hospice Foundation, Ireland

Curiale Vito, Italy

Luc Deliens, VU Medical Center, Netherlands

Hubert Jocham Home Care Akademie, Germany

Mary Lou Kelley, Lakehead University, Canada

Frank Kittelberger, Fachstelle Hospizarbeit & Palliativkultur, Germany

Sophie Pautex, University Hospital, Genève, Switzerland

Jenny van der Steen, VU Medical Center, Netherlands

Marie-Claire Van Nes, CHR de la Citadelle, Liège, Belgium

Membership of the advisory group will be confirmed once the proposal has been approved by the EAPC, but all the above people have expressed an interest in being involved in this work.

We also have a wider network of at least 50 other individuals who are interested in this area of work and will be involved in the identification of good practice examples and dissemination activities.

^{*}Co-directors of the taskforce

4) Timetable and Project Milestones Emploi du Temps **December 2009 – April 2010**: The first step of the core group will be to send the project outline to all interested experts including the advisory group to inform and ask for feedback regarding the development of the proposal. Identification of further interested people for the network will take place.

Spring 2010 MILESTONE 1:

International publication of examples of good practice of Palliative Care in Long-Term Care-Settings will be published in a book chapter (by K Froggatt, E Reitinger, J Hockley and K Brazil) for a book on Palliative Care and Older people (edited by M Gott and C Ingleton) *May – June 2010*: Preparation for the initial meeting in Glasgow with the core group and advisory group.

June 2010 MILESTONE 2: Initial meeting of the task group advisory group during the EAPC-Research congress in Glasgow (Invitation only).

- Task 1: Define long-term care settings and understandings of Palliative Care in this context
- Task 2: Present and confirm typology for classification of initiatives
- Task 3: Identify sampling strategy for survey of initiatives
- **Task 4:** Plan update on Taskforce's work to date to be submitted to the *European Journal* of *Palliative Care*

July 2010 – December 2010: Identify initiatives for the development of palliative care in these settings in different countries through:

- (i) documentary analyses (on the basis of the work of the EAPC-task-force Palliative Care for Older People: Better Practice) and;
- (ii) a survey across 10 European countries through the international organisations, government departments and networks

January 2011 – May 2011: Map activities across countries and identify different types of interventions

June 2011 MILESTONE 3: Second meeting of task group advisory group at the 12th EAPC conference in Lisbon (invited meeting)

- Task 1: Presentation of findings about mapping of activities to advisory group
- Task 2: Develop plans for compilation of compendium (invited meeting

Task 3: Present findings of mapping activities to conference (submitted as an abstract) **December 2011 MILESTONE 4:** E-publication of the Compendium, presentation of report to the EAPC and submission of a peer reviewed paper about the task-group's work to *Palliative Medicine*.

5) Financial Plan *Plan financier* The members of the core group will support this work within their current roles. Specific funding to develop different aspects of the work (eg the Compendium of good practice) will be sought from national and European institutions and research funds.

6) Project summary / abstract Résumé du projet There is growing interest across Europe and other developed countries in the provision of palliative care in nursing homes for older people and other similar long term care settings. A significant proportion of older people die in such care settings (approximately 20% in the UK). Older people living in such settings often have complex trajectories of dying: many people live with non-cancer co-morbidities, and there is a high prevalence of dementia in this population. This raises challenges for medical and nursing practitioners in terms of their management of physical and psychological symptoms and other aspects of palliative care. Working with long term care settings also requires palliative care specialists to consider issues of organisational change as new initiatives are developed between these two disciplines.

Given the marginalization of these institutions for older people in mainstream society with respect to funding for care, and research, there is a need to maximize our resources and expertise. We recognise the need to share good practice between countries and also between palliative care specialists and long term care practitioners.

At the last three EAPC conferences (Budapest (2007), Trondheim (2008) and Vienna (2009) informal meetings have been held about palliative care in long term care settings attracting between 15 and 30 participants from twelve countries. Two invited symposia on long term care and palliative care have also been on the conference programme in 2007 and 2009. A website has been established that seeks to promote this work: Palliative Care and Long Term Care Settings for Older People: Worldwide Resources (See http://www.eolc-observatory.net/information/ltc/) as described in the following publication:

Froggatt K and Heimerl K (2008) Palliative Care in Long-Term Care Settings for Older People: An International Perspective. *European Journal of Palliative Care*. 15(5): 244-247.

Within the discussions at these conferences we have identified a need to formalise our activity within the EAPC and to undertake a specific time limited piece of work that will synthesise much of the activity already being undertaken in this area. We will build our synthesis upon recent work undertaken on the EAPC task force Palliative Care for Older People: Better Practice which identified within its remit initiatives specifically in the long term care sector.

The task-group will undertake the following tasks:

- Define long term care settings and the nature of palliative care in these settings for both the palliative care world and the long-term care world.
- Undertake a documentary analysis of data submitted to the Palliative Care for Older People: Better Practice (preliminary disucssions have taken place to arrange permission for this)
- Undertake a survey of key professionals and organisations to identify initiatives being undertaken to develop the provision of palliative care in long term care settings
- Map these inititiatives by country
- Collate and create a compendium of good practice interventions for long-term care settings and palliative care practitioners

7) Other Institutions proposed for collaboration Eventuelles autres institutions proposées pour une collaboration	 EAPC task force: Palliative Care for Older People: Better Practice EAPC task force on Palliative Care for people with dementia PRISMA Alzheimer Europe European Association of Gerontology and Geriatrics6. EUGMS: Europear Union Geriatric Medicine Society
8) Support requested from the EAPC Board of Directors, Head Office and /or EAPC Committees Support demandé au Comité Directeurs, Secrétariat Général et / ou autres comités de l'EAPC	 Agree the proposal as a EAPC task force Offer a web-space at the EAPC-Homepage Support for meetings at EAPC conferences and congresses with the provision or rooms, mailings and publicity Feedback on documents produced by the taskforce

Date______Signature_____

Computer-filled and computer-signed form is accepted!