

#### 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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## EAPC Task Force on Family Carers Update for meeting on 10<sup>th</sup> May 2009

Since its inception the modern hospice and palliative care movement has recognised the important role that family carers play in providing care and support to patients. As a consequence, health and social care professionals are obliged to support the family alongside the person diagnosed with a life threatening illness. There is increasing evidence that family and other informal carers face many demands and experience considerable physical, psychological, social and financial challenges. Despite this, there has been limited research on how best to support family carers, limited research funding and only a small group of researchers actively exploring this area.

The **EAPC Task Force on Family Carers** was established in October 2008. It has the following initial *working party* lead by Professor Sheila Payne (UK) and Dr Peter Hudson (Australia) including: Professor Carol Tishelman, Professor Carl-Johan Fürst, Tove Bylund Grenklo (Sweden); Professor Phillip Larkin (Ireland); Dr Sabine Pleschberger (Austria) and Dr Gunn Grande, Dr Gail Ewing, David Oliviere, Pam Firth (UK). Since then we have been joined by Claudia Wenzel (Austria) and Carina Persson (Sweden). The working party will ensure that where pertinent there is a suitable level of engagement with relevant European clinicians, academics and managers in order to progress the taskforce objectives.

Objectives	Outcomes	Timescale (from time of EAPC endorsement of task force October 2008)
1. Evidenced based description of family carers' needs in palliative care and strategies for staff and managers in hospices and palliative care organizations regarding optimal ways to work in partnership with family carers for the benefit of both patients and family carers.	'White paper' EAPC document and Publication submitted to peer reviewed journal	Funding has been obtaining and this work will start at the end of April 2009. It is anticipated that a draft paper will be circulated in summer 2009.
2. Literature review of assessment tools for family carers	Publication submitted to peer reviewed journal	This work has been led by Peter Hudson and his team in Melbourne, Australia. They have identified 62 instruments, developed rigorous evaluation criteria to assess each measure. It is anticipated that a report will be prepared and then a paper for publication.





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3. Comparative overview of national policies in support of family carers for terminally ill patients in selected countries	EAPC Report and Publication submitted to peer reviewed journal	18 months
4.Preparation of an international survey of family carer support services provided in selected European countries (dependant upon successful funding)	Report and Publication submitted to peer reviewed journal	24 months

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