



International Palliative Care Family-carer Research Collaboration

Newsletter

April 2021

Introducing the Management Committee of the EAPC Family Carers Reference Group

The role of the EAPC Family Carers Reference Group Management Committee is to oversee the strategic direction of the IPCFRC as well as promoting the IPCFRC in their region. The Management Committee comprise members from Canada, United States, United Kingdom, Belgium, Czech Republic, Netherlands, Sweden and Australia.

More information on the EAPC Family Carers Reference Group, as well as the current list of the group's Management Committee members are available at: <https://www.eapcnet.eu/eapc-groups/reference/family-carers/>

Supporting someone with breathlessness – A source of help and advice for family and friends supporting someone with breathlessness due to COPD or cancer

The Learning about Breathlessness (LaB) research programme has developed a website for informal carers of patients with breathlessness. It is evidence-based, mapped to carers' learning needs and preferences, and can be used by carers on their own, explored in peer- or clinician-led support groups, or in one-to-one sessions between clinicians and carers (and patients). The website is now live at: <https://supporting-breathlessness.org.uk/> – please do take a look, explore it and share it with your networks. For more information, please contact Dr Morag Farquhar, LaB Program Lead, at: LaB.2@uea.ac.uk

EAPC Task Force on Costs of Family Caregiving in Palliative Care

The EAPC Family Carers Reference Group is linked with the EAPC Task Force on Costs of Family Caregiving in Palliative Care. The task force aims to establish an international network of researchers, clinicians, policymakers with an interest in research on the costs of caring in palliative care, and form the basis of an international, multidisciplinary research collaboration with the aim of furthering the research agenda on the costs of family caring in palliative care. Find out more about the task force [\[here\]](#).

IPCFRC is a Reference Group of the European Association for Palliative Care (EAPC) and is administered in partnership with the Centre for Palliative Care, St. Vincent's Hospital and a Collaborative Centre of the University of Melbourne, Australia.

Email: centre.palliativecare@svha.org.au or Telephone: +61 3 9416 0000

Published literature related to family carer research

One of the initiatives of the EAPC Family Carers Reference Group is to compile a listing of publications related to family caregiver research in palliative care. This list is updated annually, and serves as a key resource to aid those who are looking for peer-reviewed publications related to family caregivers. The 2021 version is available as a downloadable resource on the [\[IPCFRC website\]](#).

Promoting collaboration amongst members

In order to promote collaboration amongst EAPC Family Carers Reference Group members, in the next edition of our e-newsletter we will be sending out a list detailing all of IPCFRC members' affiliations, email address, and areas of research interest. This list (which will be circulated to IPCFRC members only) will make it easier for members to contact other members directly about potential research collaborations.

If you are an IPCFRC member and you would prefer that your details ARE NOT included for circulation, please inform us as soon as possible via email to: centre.palliativecare@svha.org.au. If we did not hear back from you by 8 May 2021, we will presume that you give consent for your details to be published to the membership.

Please note that the list will only be circulated to IPCFRC members. If you would like to become a member, please see the directions under the 'Membership' section of this newsletter.

Membership

The EAPC Family Carers Reference Group (IPCFRC) has 314 registered members from many countries of the world, including: Australia, Brazil, Canada, Denmark, France, Germany, India, Iran, Ireland, New Zealand, Nigeria, Norway, Spain, Sweden, South Africa, Thailand, UK and USA. Institutional collaborators of IPCFRC include: [Centre for Palliative Care](#) (a department of [St Vincent's Hospital Melbourne](#) and a Collaborative Centre of [The University of Melbourne](#)), Melbourne, Australia; [International Observatory on End of Life Care \(IOELC\)](#), Lancaster University, UK; [St Christopher's Hospice](#), UK; and [The Palliative Care Research Cooperative Group \(PCRC\) - Caregiver Core](#), Denver, USA.

Individuals from all continents with a genuine interest in palliative care research related to family carers may become individual members of the IPCFRC. **Membership is FREE**. To formalise your membership please complete the [\[online form\]](#) on the IPCFRC website.

Upcoming Event

The EAPC Family Carers Reference Group will hold a parallel session at the upcoming 17th World Congress of the European Association for Palliative Care (EAPC 2021) on:

***“Strategies to improve psychosocial wellbeing of family carers:
How international collaborations make a difference”***

The session is targeted at multidisciplinary health care workers and researchers who want to improve support for family carers, and aims to provide attendees with the following:

- Insights into the value of international collaborations to improve palliative care service delivery and how to get involved;
- Understanding of why so many family carers are at risk of poor psychosocial wellbeing;
- The value of using evidence based outcome measures to assess psychosocial wellbeing;
- Opportunities to meet and connect with leaders in family carer research and evidence based practice.

Session Chairs:

- Professor Gunn Grande (The University of Manchester, UK)
- A/Prof Nick Dionne-Odom (University of Alabama at Birmingham, USA)

Presentations include:

“Evidence synthesis of factors affecting family carers’ psychological wellbeing”

by Dr Tracey Shield and Professor Gunn Grande, The University of Manchester, UK.

“Supporting family carer decision-making in palliative dementia care”

by Professor Kevin Brazil, Queen's University Belfast, UK.

“Key considerations when selecting family carer outcome measures”

by A/Prof Nick Dionne-Odom, University of Alabama at Birmingham, USA.

Further information on the session date and time will be available on the [\[EAPC website\]](#).

Conferences relevant to IPCFRC members

Please note: due to COVID-19, please check the relevant conference websites for the most recent updates/information on conference status and dates.

22nd World Congress on Psycho-oncology and Psychosocial Academy (IPOS 2021)

Dates: May 26-29, 2021

Location: Virtual

Website: [\[IPOS 2021\]](#)

24th International Philosophy of Nursing Conference IPONS. Personhood: philosophies, applications and critiques in healthcare (IPONS 2021)

Dates: June 16-18, 2021

Location: Virtual / Gothenburg, Sweden

Website: [\[IPONS 2021\]](#)

Oceanic Palliative Care Conference 2021 (PCA 2021)

Dates: September 7-10, 2021

Location: Virtual

Website: [\[PCA 2021\]](#)

17th World Congress of the European Association for Palliative Care (EAPC 2021)

Dates: October 6-8, 2021

Location: Virtual

Website: [\[EAPC 2021\]](#)

14th Asia Pacific Hospice Conference

Dates: November 13-14, 2021

Location: Virtual

Website: [\[APHC 2021\]](#)

Recent articles relevant to EAPC Family Carers Reference Group (IPCFRC) members

In each edition we will feature some recently published articles relevant to IPCFRC members.

If you have published in a peer-reviewed journal recently and the subject matter is relevant to the IPCFRC community, please email centre.palliativecare@svha.org.au with the subject 'IPCFRC Newsletter' and we will feature your publication in an upcoming edition.

Breen LJ, Johnson AR, O'Connor M, Howting D, Aoun SM. (2021). Challenges in Palliative Care Research on Family Caregivers: Who Volunteers for Interviews? *J Palliat Med.* 24(1):112-115.

Gardiner, C., Robinson, J., Connolly, M. et al. (2020). Equity and the financial costs of informal caregiving in palliative care: a critical debate. *BMC Palliat Care* 19:71.

Grant M, Hudson P, Forrest A, Collins A, Israel F. (2021). Developing a model of bereavement care in an adult tertiary hospital. *Aust Health Rev.* 45(1):110-116.

Porter LS, Steel JL, Fairclough DL, LeBlanc TW, Bull J, Hanson LC, Fischer S, Keefe FJ. (2021). Caregiver-guided pain coping skills training for patients with advanced cancer: Results from a randomized clinical trial. *Palliat Med.* doi: 10.1177/02692163211004216. [Epub ahead of print]

Sato T, Fujisawa D, Arai D, Nakachi I, et al. (2021). Trends of concerns from diagnosis in patients with advanced lung cancer and their family caregivers: A 2-year longitudinal study. *Palliat Med.* doi: 10.1177/02692163211001721. [Epub ahead of print]

Spatuzzi R, Giulietti MV, Romito F, et al. (2021). Becoming an older caregiver: A study of gender differences in family caregiving at the end of life. *Palliat Support Care.* doi: 10.1017/S1478951521000274. [Epub ahead of print]

Would you like to be profiled in the EAPC Family Carers Reference Group e-News?

One of the key objectives of the EAPC Family Carers Reference Group (IPCFRC) is to encourage researchers interested in family caregiver research to make connections and collaborate. To help enable this we would like to offer members the opportunity to be profiled in the IPCFRC e-News. One researcher will be profiled within each edition.

If you are interested in being considered, please provide the details below to centre.palliativecare@svha.org.au with the subject 'IPCFRC member profile'.

Please provide the following details: Your Name, Professional Role/Title, Discipline, Institution, City/Country, Specific area of interest in family caregiver research and your Email address (so that other members can contact you directly).

Forward our E-News to your networks!

Please forward this newsletter to friends or colleagues interested in family carer research. They can also sign up for [\[free membership\]](#)!

Unsubscribe

If you are no longer interested in receiving correspondence from us, please unsubscribe by emailing: centre.palliativecare@svha.org.au