



International Palliative Care Family-carer Research Collaboration  
(EAPC Family Carer Reference Group)

# Newsletter

July 2021

## Upcoming Event

The IPCFRC EAPC Family Carer Reference Group will hold a parallel session at the upcoming 17<sup>th</sup> 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 [\[EAPC website\]](#).**

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](mailto:centre.palliativecare@svha.org.au) or Telephone: +61 3 9416 0000

## Promoting collaboration amongst members

In order to promote collaboration amongst IPCFRC EAPC Family Carer Reference Group members, we have attached a membership listing (detailing members' affiliations, email address, and areas of research interest) with this edition of e-newsletter. We encourage you to contact other members with similar interests in order to promote collaboration.

***Please note that this membership listing is intended for IPCFRC EAPC Family Carer Reference Group members' information only and is not for redistribution.***

If you would like to become a member, please refer to the 'Membership' section of this newsletter.

## EAPC Task Force on Costs of Family Caregiving in Palliative Care

The IPCFRC EAPC Family Carer Reference Group is linked with the EAPC Task Force on Costs of Family Caregiving in Palliative Care. The taskforce 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 taskforce [\[here\]](#).

## Published literature related to family carer research

One of the initiatives of the IPCFRC EAPC Family Carer 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 [\[IPCFRC website\]](#).

## Membership

The IPCFRC EAPC Family Carer Reference Group has 324 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 the IPCFRC EAPC Family Carer Reference Group 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 EAPC Family Carer Reference Group. **Membership is FREE.** To formalise your membership please complete the [\[online form\]](#) on the IPCFRC EAPC Family Carer Reference Group website.



## Conferences relevant to IPCFRC EAPC Family Carer Reference Group members

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

Oceanic Palliative Care Conference 2021 (PCA 2021)

Dates: September 7-10, 2021

Location: Virtual

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

17<sup>th</sup> World Congress of the European Association for Palliative Care (EAPC 2021)

Dates: October 6-8, 2021

Location: Virtual

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

14<sup>th</sup> Asia Pacific Hospice Conference

Dates: November 13-14, 2021

Location: Virtual

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

48<sup>th</sup> Clinical Oncology Society of Australia (COSA) Annual Scientific Meeting

Dates: November 16-18, 2021

Location: Melbourne VIC, Australia

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

3<sup>rd</sup> and 4<sup>th</sup> Sapporo Conference for Palliative and Supportive Care in Cancer

Dates: July 21-23, 2022

Location: Sapporo, Japan

Website: [\[SCPSC 2022\]](#)

23<sup>rd</sup> International Congress on Palliative Care

Dates: October 18-21, 2022

Location: Montréal, Canada

Website: [\[ICPC 2022\]](#)

## Recent articles relevant to IPCFRC EAPC Family Carer Reference Group members

In each edition we will feature some recently published articles relevant to IPCFRC EAPC Family Carer Reference Group members. If you have published in a peer-reviewed journal recently and the subject matter is relevant to the IPCFRC EAPC Family Carer Reference Group community, please email [centre.palliativecare@svha.org.au](mailto:centre.palliativecare@svha.org.au) with the subject 'IPCFRC Newsletter' and we will feature your publication in an upcoming edition.

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Dierickx S, Beernaert K, Faes K, Verhaert R, Chambaere K. (2021). The added value of palliative day care centres: A full-population cross-sectional survey among clients and their family caregivers in Flanders, Belgium. *Health Soc Care Community*. doi: 10.1111/hsc.13467. [Epub ahead of print]

Dionne-Odom JN, Azuero A, Taylor RA, Wells RD, Hendricks BA, Bechthold AC, Reed RD, Harrell ER, Dosse CK, Engler S, McKie P, Ejem D, Bakitas MA, Rosenberg AR. (2021). Resilience, preparedness, and distress among family caregivers of patients with advanced cancer. *Support Care Cancer*. doi: 10.1007/s00520-021-06265-y. [Epub ahead of print]

Hochwald IH, Yakov G, Radomyslsky Z, Danon Y, Nissanholtz-Gannot R. (2021). Ethical challenges in end-stage dementia: Perspectives of professionals and family care-givers. *Nurs Ethics*. doi: 10.1177/0969733021999748. [Epub ahead of print]

Juraskova I, Laidsaar-Powell R, Keast R, Schofield P, Costa DS, Kay J, Turner S, Koczwara B, Saunders C, Jefford M, Yates P, Boyle F, White K, Miller A, Morton RL, Butt Z, Butt P. (2021). eTRIO trial: study protocol of a randomised controlled trial of online education modules to facilitate effective family caregiver involvement in oncology. *BMJ Open* 11(5):e043224. doi: 10.1136/bmjopen-2020-043224.

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## Recent articles relevant to IPCFRC EAPC Family Carer Reference Group members

*Continued...*

Lall P, Dutta O, Tan WS, Patinadan PV, Kang NQY, Low CK, Car J, Ho AHY. (2021). "I decide myself"- A qualitative exploration of end of life decision making processes of patients and caregivers through Advance Care Planning. PLoS One 16(6):e0252598. doi: 10.1371/journal.pone.0252598.

Lilleheie I, Debesay J, Bye A, Bergland A. (2021). The tension between carrying a burden and feeling like a burden: a qualitative study of informal caregivers' and care recipients' experiences after patient discharge from hospital. Int J Qual Stud Health Well-being. 16(1):1855751. doi: 10.1080/17482631.2020.1855751.

Washington KT, Benson JJ, Chakurian DE, Popejoy LL, Demiris G, Rolbiecki AJ, Oliver DP. (2021). Comfort Needs of Cancer Family Caregivers in Outpatient Palliative Care. J Hosp Palliat Nurs. 23(3):221-228. doi: 10.1097/NJH.0000000000000744.

Weaver MS, Wiener L, Moon MM, Gordon B, Kelly KP, Hinds PS. (2021). Family Caregiver Partnerships in Palliative Care Research Design and Implementation. Pediatrics. doi: 10.1542/peds.2020-049403. [Epub ahead of print]

Wu MP, Tsao LI, Huang SJ, Liu CY. (2021). Development of the Readiness for Home-Based Palliative Care Scale (RHBPCS) for Primary Family Caregivers. Healthcare (Basel) 9(5):608. doi: 10.3390/healthcare9050608.



### Featured Member

Professor Erica Witkamp, *PhD*  
Management Committee member – IPCFRC EAPC Family  
Carer Reference Group

*Applied Research Professor (Lector) Care for Family Caregiving,  
Rotterdam University of Applied Sciences;  
Senior Researcher,  
Erasmus University Medical Center  
Research Centre Innovations in Care and Faculty of Nursing  
Rotterdam University of Applied Sciences  
Rotterdam, Netherlands*

**Erica Witkamp, PhD** trained as a nurse and health scientist in the Netherlands. She has extensive experience in home care and palliative oncology care. She obtained her PhD in 2015 for her research into quality of dying in hospital. Erica works as an applied research professor at the Research Center Innovations in Care and as a senior lecturer in the Bachelor of Nursing Program at the Rotterdam University of Applied Sciences in the Netherlands. She is also a senior researcher at the Department of Public Health at Erasmus University Medical Center. Erica's work focuses on family caregivers of patients with severe chronic and/or terminal conditions. Erica is involved in various research projects aimed at improving support for family caregivers in dealing with the impact of disease on their relatives, as well as improving collaboration between family caregivers, patients and health care professionals.

*If you would like to know more about Professor Witkamp and her work, you can contact her directly at [f.e.witkamp@hr.nl](mailto:f.e.witkamp@hr.nl)*



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

One of the key objectives of the IPCFRC EAPC Family Carer Reference Group 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 EAPC Family Carer Reference Group 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](mailto: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 [\[free membership\]](#)!

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