



Centre for
Palliative Care
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StChristopher's

International Palliative Care Family-carer Research Collaboration

Newsletter

March 2018

Survey: Financial support for family caregivers of patients at the end of life

You are invited to complete a survey about financial support for family caregivers of patients receiving palliative care or with life limiting conditions, as part of the project led by Dr Clare Gardiner from the University of Sheffield, UK, to map the financial support available for family carers of terminally ill patients across seven countries (UK, Australia, NZ, USA, Canada, Ireland and Norway). More information about this study is accessible [\[here\]](#).

To participate in the survey, please click [\[here\]](#).

Contact for further information: Clare Gardiner, The University of Sheffield, School of Nursing & Midwifery, Barber House Annexe, 3a Clarkehouse Rd, Sheffield, S102LA | Tel: (0114) 222 2038 |
E-mail: c.gardiner@sheffield.ac.uk

Would you like to be profiled in the IPCFRC e-News?

One of the key objectives of the 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).

Review of literature related to family carer research

One of the initiatives of the IPCFRC 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 2018 version is available as a downloadable resource on the [\[IPCFRC website\]](#).

Membership

The IPCFRC has 243 registered members from many countries of the world, including; Australia, Bulgaria, Cameroon, Canada, Denmark, France, Germany, Ireland, Japan, New Zealand, Nigeria, Norway, Spain, Sweden, Thailand, UK & 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 IPCFRC Events

1. An open meeting for current and prospective IPCFRC members at the [10th World Research Congress of the European Association for Palliative Care (EAPC) in Bern, Switzerland] on Friday 25th May 2018 at 1.30-2.00pm (Location: Sopra Grande Room, Kursaal Berne). Meeting Chair: Professor Peter Hudson. All Congress delegates are welcome to attend (free of charge).

2. Another open meeting will also be held at the [22nd International Congress on Palliative Care in Montreal], on Wednesday 3rd October at 1.15-1.45pm (Location: Palais de congrès – Actual room location TBC on the on-site Congress Programme). Meeting Co-Chairs: Professor Peter Hudson (Australia) and Professor Kelli Stajduhar (Canada). All Congress delegates are welcome to attend (free of charge).

Open meetings provide the opportunity for members and prospective members to hear about what is happening in the IPCFRC community and what IPCFRC has to offer, as well as meet the IPCFRC Executive Committee and their fellow IPCFRC members.

Conferences relevant to IPCFRC members

13th Annual Conference on Palliative and End of Life Care

Dates: May 4, 2018

Location: Ontario, Canada

Website: [\[ACPEL 2018\]](#)

Palliative Care Nurses Australia (PCNA) Conference 2018

Dates: May 20-21, 2018

Location: Brisbane QLD, Australia

Website: [\[PCNA 2018\]](#)

10th World Research Congress of the European Association for Palliative Care (EAPC)

Date: May 24-26, 2018

Location: Bern, Switzerland

Website: [\[EAPC 2018\]](#)

Primary Care Collaborative Cancer Clinical Trials Group (PC4) Scientific Symposium 2018

Date: May 25, 2018

Location: Sydney NSW, Australia

Website: [\[PC4 2018\]](#)

International Death, Grief & Bereavement Conference 2018

Dates: June 4-6, 2018

Location: Chicago, USA

Website: [\[DGB 2018\]](#)

21st Cancer Nurses Society of Australia (CNSA) Annual Congress

Dates: June 21-23, 2018

Location: Brisbane QLD, Australia

Website: [\[CNSA 2018\]](#)

Multinational Association of Supportive Care in Cancer (MASCC)/ International Society of Oral Oncology (ISOO) Annual Meeting on Supportive Care in Cancer 2018

Dates: June 28-30, 2018

Location: Vienna, Austria

Website: [\[MASCC/ISOO 2018\]](#)

Australian and New Zealand Society of Palliative Medicine (ANZSPM) Annual Conference 2018

Dates: September 6-9, 2018

Location: Sydney NSW, Australia

Website: [\[ANZSPM 2018\]](#)

22nd International Congress on Palliative Care

Dates: October 2-5, 2018

Location: Montreal, Canada

Website: [\[ICPC 2018\]](#)

6th Australian Palliative Care Research Colloquium

Dates: October 25-26, 2018

Location: Melbourne VIC, Australia

Website: [\[APCRC 2018\]](#)

20th IPOS World Congress of Psycho-Oncology

Dates: October 31- November 2, 2018

Location: Hong Kong

Website: [\[IPOS 2018\]](#)

45th Clinical Oncology Society of Australia (COSA) Annual Scientific Meeting

Dates: November 13-15, 2018

Location: Perth WA, Australia

Website: [\[COSA 2018\]](#)

Recent articles relevant to 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.

Dionne-Odom JN, Taylor R, Rocque G, Chambless C, et al. (2018). Adapting an Early Palliative Care Intervention to Family Caregivers of Persons with Advanced Cancer in the Rural Deep South: A Qualitative Formative Evaluation. *J Pain Symptom Manage*. doi: 10.1016/j.jpainsymman.2018.02.009. [Epub ahead of print]

Ewing G, Austin L, Jones D, Grande G. (2018). Who cares for the carers at hospital discharge at the end of life? A qualitative study of current practice in discharge planning and the potential value of using The Carer Support Needs Assessment Tool (CSNAT) Approach. *Palliat Med*. doi: 10.1177/0269216318756259. [Epub ahead of print]

Green E, Knight S, Gott M, Barclay S, White P. (2018). Patients' and carers' perspectives of palliative care in general practice: A systematic review with narrative synthesis. *Palliat Med*. doi: 10.1177/0269216317748862. [Epub ahead of print]

Heath A, Carey LB, Chong S. (2018). Helping Carers Care: An Exploratory Study of Factors Impacting Informal Family Carers and Their Use of Aged Care Services. *J Relig Health*. doi: 10.1007/s10943-018-0593-3. [Epub ahead of print]

Lalani N, Duggleby W, Olson J. (2018). Spirituality among family caregivers in palliative care: an integrative literature review. *Int J Palliat Nurs*. 24(2):80-91.

Leonard R, Horsfall D, Rosenberg J, Noonan K. (2018). Carer experience of end-of-life service provision: a social network analysis. *BMJ Support Palliat Care*. doi: 10.1136/bmjspcare-2017-001344. [Epub ahead of print]

Lin JJ, Smith CB, Feder S, Bickell NA, Schulman-Green D. (2018). Patients' and oncologists' views on family involvement in goals of care conversations. *Psychooncology*. doi: 10.1002/pon.4630. [Epub ahead of print]

Mohammed S, Swami N, Pope A, Rodin G, et al. (2018). "I didn't want to be in charge and yet I was": Bereaved caregivers' accounts of providing home care for family members with advanced cancer. *Psychooncology*. doi: 10.1002/pon.4657. [Epub ahead of print]

Odgers J, Penney W, Fitzpatrick D, Shee AW. (2018). No one said he was dying: families' experiences of end-of-life care in an acute setting. *Aust J Adv Nurs*. 35(3): 21-31.

Pask S, Pinto C, Bristowe K (et al). (2018). A framework for complexity in palliative care: A qualitative study with patients, family carers and professionals. *Palliat Med*. doi: 10.1177/0269216318757622. [Epub ahead of print]

Roze des Ordon A, Sinuff T, Stelfox HT, et al. (2018). Spiritual distress within inpatient settings – A scoping review of patient and family experiences. *J Pain Symp Manage*. doi: 10.1016/j.jpainsymman.2018.03.009. [Epub ahead of print]

Stiel S, Heckel M, Wendt KN, Weber M, et al. (2018). Palliative Care Patients' Quality of Dying and Circumstances of Death – Comparison of Informal Caregivers' and Health-Care Professionals' Estimates. *Am J Hosp Palliat Med*. doi: 10.1177/1049909118756616. [Epub ahead of print]

Thomas C, Turner M, Payne S, Milligan C, et al. (2018). Family carers' experiences of coping with the deaths of adults in home settings: A narrative analysis of carers' relevant background worries. *Palliat Med*. doi: 10.1177/0269216318757134. [Epub ahead of print]

Yoo SH, Yun YH, Kim KN, Lee JL, et al. (2018). The impact of caregiver's role preference on decisional conflicts and psychiatric distresses in decision making to help caregiver's disclosure of terminal disease status. *Qual Life Res*. doi: 10.1007/s11136-018-1814-7. [Epub ahead of print]

Forward IPCFRC to a friend!

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

Update your details!

We are now collecting information on member research interests and expertise. [\[Update your details now\]](#)

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