

mySupport

FAMILY CARER DECISION SUPPORT STUDY

Welcome to the sixth edition of mySupport study newsletter. We are now into the third year of mySupport study. The aim of the study is to adapt, implement and evaluate the [Family Carer Decision Support](#) intervention in six countries: United Kingdom, Republic of Ireland, Netherlands, Canada, Czech Republic, and Italy.

The pandemic has led to some variation in the timelines for the study across the six countries, however families have now been recruited across all sites, with data collection well underway.

The past almost two years have been an extremely challenging time for everyone, and no one more so than nursing home staff and residents and their families. We would like to thank all study participants, who despite this have participated in the mySupport study.

The latest **blogs** on the mySupport Study website include:

[Changes to Dutch policy on care homes and the impact to older adults](#)

Marianne Van Brussel, mySupport study Strategic Guiding Council member (Netherlands)

[How can we support family caregivers of people with an intellectual disability and dementia?](#)

Caroline Lennon-Nally, mySupport study Strategic Guiding Council member, and Maria Nicula, McMaster University (Canada)

[Supporting the Implementation of Comfort Care at the End-of-Life](#)

Bianca Tétrault, McGill University (Canada)

[Being on one ship: Developing trust between family carers and nursing home staff requires effective communication](#)

Hana Convoy, mySupport study Strategic Guiding Council member and Karolína Vlčková, Center for Palliative Care (Czech Republic)

[An International Early Career Research Committee – Members' Experiences](#)

Dr Adrienne McCann, Queen's University Belfast (Northern Ireland)

[Establishing an International Early Career Research Committee and Mentorship Programme](#)

Dr Serena FitzGerald, University College Cork (Ireland)

KEY ACTIVITIES

The Family Carer Decision Support intervention consists of three components: training of nursing home staff, the provision to families of a Comfort Care Booklet about end-of-life care and the care options for people living with advanced dementia, and delivery of a Family Care Conference.

Despite delay staff training has now been completed at all sites. Family care conferences have been held in all sites, with family recruitment completed in some and still ongoing in others. Interviews with staff and families are being conducted before and after the intervention to see how the intervention worked and how it could be rolled out to other nursing homes in the future.

Our mySupport study partners across the six countries continue to meet monthly in order to support the implementation and evaluation of the intervention across the sites. The knowledge translation and exchange (KTE) champion group is continuing to meet every six weeks to support the intervention uptake at the various sites.

Additionally, a number of working groups have been established to oversee the management and analysis of qualitative and quantitative data. Bi-monthly case study meetings to discuss the development of case reports are led by Dr Emily Cousins of De Montfort University, with the next meeting due to take place in January 2022. The Czech team coordinates the working group that continues in developing the codebooks to ensure a consistent approach to the qualitative data analysis across countries and a meeting for the Guideline Development Committee is also planned for January 2022.

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Video podcast with Dr Marcel Arcand

The Canadian and Irish teams have been working on a two-part video podcast with Dr Marcel Arcand which is now available with subtitles in all partner languages. The video podcasts are available with subtitles on the mySupport website.

Dr Arcand is the author of the [Comfort Care at End-of-Life booklet](#), which is given to families as part of the Family Carer Decision Support intervention implemented and evaluated by the mySupport study.

In this two-part video podcast, Dr Arcand describes how end-of-life care can be implemented for individuals with advanced dementia. He also explains the features of a “low-tech high-touch” approach to care and the vital role of family carers to this approach. Bianca Tétrault of McGill University, who was involved in the development of the videos, previously outlined the features of this approach in the [July Newsletter](#).

We would like to thank everyone involved in the production of these videos, in particular John McKeown and [The Sixsem Production Company](#).

Scientific Journal Submissions

Bavelaar, L., van Tol, L.S., Caljouw, M.A.A. et al. Nederlandse vertaling en eerste stappen in validatie van de PPEET om burger- en patiëntenparticipatie te evalueren. TSG Tijdschr Gezondheidswet (2021). <https://doi.org/10.1007/s12508-021-00316-9>

Bavelaar L, Nicula M, Morris S, Kaasalainen S, Achterberg WP, Loucka M, et al. Developing country-specific questions about end-of-life care for nursing home residents with advanced dementia using the nominal group technique with family caregivers. Patient Education and Counseling. 2021/07/23/ 2021;doi:<https://doi.org/10.1016/j.pec.2021.07.031>

Gonella S, Campagna S, Angaramo M, Dimonte V, Di Giulio P. How successfully implementing a quality improvement research project in nursing home during COVID-19 pandemic times: lessons learnt from a concurrent qualitative study. Submitted to the International journal of social research methodology on November 8th, 2021.

The Dutch team led a manuscript describing a comparison between the countries' comfort care booklets. This manuscript has been submitted to a scientific journal and is currently under review.

Early Career Researcher Committee

After a brief summer hiatus, the ECRC welcomed back its members at a kick-off meeting in September. We would like to welcome our new members Emma Loudon and Julia Doherty from Queen's University, Belfast. We would like to thank last terms core committee (Danielle Just-Chair, Emily Di Sante – Co-Chair, Laura Bavelaar – Secretary, and Maria Nicula – Social Media & Activities Officer) for their enthusiasm and commitment to progressing the ECRC agenda and actions over the last year. We look forward to welcoming a new core committee in the new year. The ECRC continue to work on collaborative publications and building research capacity online. The committee hope to host an ECRC mentorship achievement event in early 2022, details of this event will be circulated in the coming weeks.

Study Presentations

Bavelaar L (2021) Guidance for family about comfort care in dementia: a comparison of an educational booklet adopted in European countries over 15 years, 31st Alzheimer Europe Conference 2021

The Czech team submitted two abstracts to the 12th World Research Congress organized by EAPC in May 2022, one based on the systematic review about methodological and ethical issues in end-of-life research and the second on barriers and facilitators for implementation of family care conferences in nursing homes in the Czech Republic.

The Dutch, Italian, and Irish teams recently submitted a symposium submission to the 26th Nordic Congress on Palliative Care with the title “Implementation of advance care planning in dementia with nursing home staff and family caregivers during Covid-19: The six-country mySupport study” Czech, nursing homes in the Czech Republic.

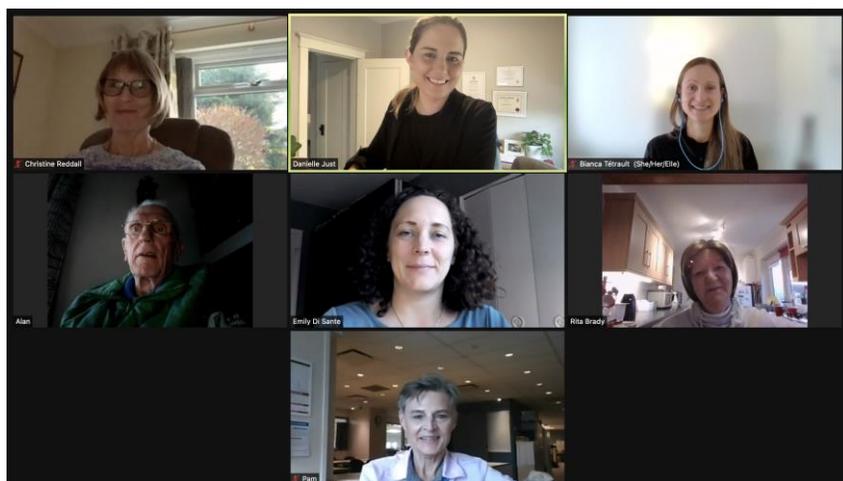
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Strategic Guidance council

The Canadian team hosted the final Strategic Guiding Council meeting in November 2021. The Strategic Guiding Council is an international patient and public involvement panel who met on a monthly basis over the past year to consult on the mySupport study. The members of the Strategic Guiding Council participated in numerous activities such as providing feedback on recruitment strategies, reviewing data collection tools, and consulting on knowledge translation projects for the mySupport study. The Strategic Guiding Council also published online articles to highlight the perspective and experiences of family carers for residents with advanced dementia. To date three Strategic Guiding Council members' online articles have been published on the mySupport website.

The Strategic Guiding Council provided invaluable support over the last 12 months and we will all be sad to see them go.



Learn more about mySupport

The mySupport Study [website](https://mysupportstudy.eu/) contains information about the study and the team, as well as research materials.

A **promotional video** is available with subtitles in all partner country languages.

<https://mysupportstudy.eu/>

Participants' Perspective

This month we have included quotes from some of our family carers participating in the mySupport Study. The aim of our study is to improve care for all residents with advanced dementia and their family members and we are delighted to receive positive feedback.

"Thank you for arranging this meeting. It was a pleasure speaking with the nurse and hearing about all the care my family member is getting. I appreciated learning how thorough the staff procedures are in caring for the residents. It puts me at ease to know that my family member is in very good hands. The care offered is full of kindness and attention. I appreciated the generous time offered to me to ask all my questions. The support means a lot to me and comforts me as I witness my family member's illness worsen. I now know better what to expect and what may happen as time passes."

- Family member at our Montreal site

"The study helped me a lot. I got the Comfort Care Booklet from a nurse and I have to say that it really helped me with my worries. I was afraid that my mum would suffer from pain and she explained everything to me about that step by step. What options are there and what they are doing for my mum at the moment. So I really left this meeting calmer, it really helped me a lot."

- Family member at one of our Czech sites

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