

mySupport

FAMILY CARER DECISION SUPPORT STUDY

Welcome to the fourth edition of mySupport study newsletter.

We are now into our second year of mySupport study. We aim 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 educational intervention has been adapted by each country and we look forward to sharing it with family carers to inform them about end-of-life care options for people living with advanced dementia.

The past year has been difficult with the COVID-19 pandemic but we are looking forward to brighter times in 2021. Most of our study sites have been busy with COVID-19 vaccination over the past few weeks. As vaccinations are completed, we will hopefully see a reduced burden on nursing homes. We are looking forward to introducing the *Comfort Care Booklet* to sites and working with staff and family carers in progressing this research further in the coming months.

Learn more about our research and related topics

Our mySupport Study **promotional video** is now available with subtitles in all partner country languages. Thanks to all who contributed to this. The video provides a description of the study and is available on our website: mysupportstudy.eu



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

[Do We All Have an Advance Care Plan?](#)

Dr. Karen Harrison Denning.

[Residents and families mourn as restrictions are imposed on visiting nursing homes during the COVID-19 pandemic.](#)

Dr Irene Hartigan.

KEY ACTIVITIES

Staff training and data collection are underway after delays due to the COVID-19 pandemic. The pandemic has led to some variation in the timelines for the study across the six countries.

The 'train-the-trainer' approach has now progressed to the next phase. In most countries, the facilitators of training have completed their online modules and are now training the staff at nursing homes who will deliver the intervention. The training in nursing homes includes a combination of online and socially-distant face-to-face sessions. A formal evaluation of the online training platform is planned in order to provide insight into the benefit of online learning environments for educating healthcare professionals.

The *Comfort Care Booklet*, which is given to families and staff as part of the intervention, has been adapted in each country. Research comparing the booklets across countries is currently being finalized to inform the future use of the booklet. Across the six countries, a number of working groups have been established to oversee the management and analysis of qualitative and quantitative data.

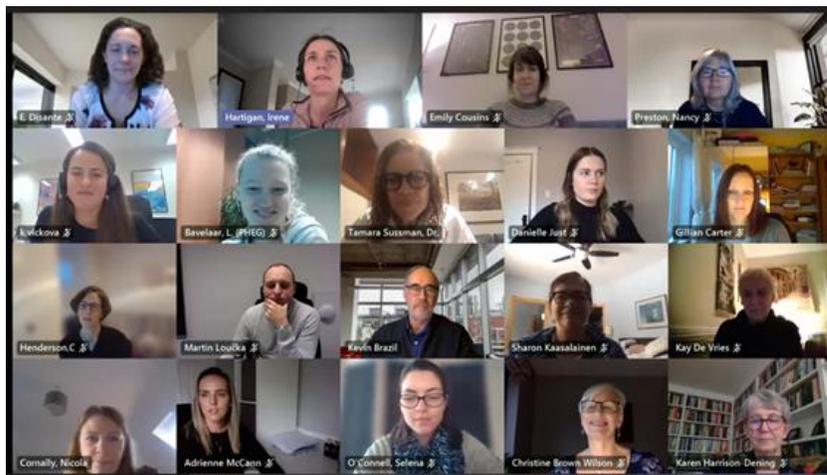
Data are being collected before and after the intervention in order to see if the intervention worked and how it worked. This includes information about the nursing homes and the perspectives of staff and family carers. Many countries have gathered data to understand the context of the nursing homes. Furthermore, a few sites have begun to recruit family members to participate in the study and nursing home staff have conducted family care conferences. These are meetings between the family and staff to discuss end-of-life care for the resident.

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Online communication across partner countries

Our mySupport Study partners across six countries continue to meet monthly in order to support the implementation and evaluation of the intervention across the sites.



Public and Patient Involvement

In November 2020, mySupport study launched the Strategic Guiding Council, an international long-term care Patient and Public Involvement (PPI) panel. The purpose of this group is to provide guidance for mySupport study from the perspective of the family carer.

There are currently 13 members, with representation from Canada, the Czech Republic, Ireland, the Netherlands and the United Kingdom. This group meets monthly to inform mySupport Study and has completed 5 feedback activities so far. The research teams in each country have also established PPI voluntary advisory groups which are made up of members of the public that have experience caring for a family member with dementia.

Meet the Researcher...

Associate Professor Paola Di Giulio

When I completed my nurse training in a cancer Institute in Milano, my research area developed to include end of life and survival of cancer patients. I was involved in a multidisciplinary research group, however I realized that while many researchers focused on cancer patients, other patient populations had only scarce information about end of life, in particular patients with advanced dementia in Nursing Homes. From this, I began my collaborations with Dr Franco Toscani. We started a long research path that has now led us to involve a growing number of Nursing Homes and districts, mainly in northern Italy, to collect data and propose research questions relevant for the care of advanced dementia patients at the end of life.

I have had different experiences from working as a nurse to teaching bachelor student nurses. One of my main interests is the promotion of nursing in research. I had the opportunity to do this through involving nurses in companion research projects (independent research projects nested in clinical trials) in my 20 years of collaboration with the Mario Negri Pharmacological research Institute. I have collaborated part-time for 15 years with a swiss University School which was beginning the transition of the training of health professions (nurses, occupational therapists, and physiotherapists) into universities.

With 20 years of experience now as an Associate Professor at the University of Turin, I have had the opportunity to write about good end of life care in nursing homes. I am currently working full time with a group of young colleagues who are very involved in research, and with whom we are carrying out research on several areas, including end-of-life communication with patients with advanced dementia.

I am also an editor for the nursing journal (Assistenza Infermieristica e Ricerca) which is 40 years old this year, and which has always sought to promote the link between research and practice and the importance of research for the nursing profession.



[Link to University Profile](#)

Recent publications:

Toscani, F., Finetti, S., Giunco, F. et al. The last week of life of nursing home residents with advanced dementia: a retrospective study. *BMC Palliative Care* 18, 117 (2019). [\(Link\)](#)

Gonella, S., Basso, I., De Marinis, M. G., Campagna, S., & Di Giulio, P. (2019). Good end-of-life care in nursing home according to the family carers' perspective: A systematic review of qualitative findings. *Palliative medicine*, 33(6), 589-606. [\(Link\)](#)

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Early Career Researchers' Committee (ECRC)

The ECRC continues to be an active forum for early career researchers in the mySupport Study. Over the past few months, the following members have presented at our monthly committee meetings:

- ❖ Karolína Vlčková (Centre of Palliative Care, Czech Republic) presented on “Comparing methods for assessing quality of life in palliative care”.
- ❖ Dr Adrienne McCann (Queens University Belfast) presented on “Measuring Cognitive Impairment in Older Adults: MMSE vs MoCA”.
- ❖ Dr Selena O' Connell (University College Cork) presented on “An overview of discrete choice experiment methods and their application to understanding preferences for end-of-life care”.

We have also organised several external workshops. Dr Diana Sherifali and Laura Banfield from McMaster University joined us to discuss the process of conducting a scoping literature review. We were also delighted to welcome Emeritus Professor Eileen Savage from University College Cork who joined us to host a workshop on “Mastering your Best Self towards Research Leadership & Career Aspirations” (pictured below).



The ECRC mentorship programme has been awarded a digital badge through the Centre of Digital Education, University College Cork. Our mentorship programme links early career researchers with more experienced members of the team to foster career progression.

The progression phase of the mentorship programme is almost complete. Our members are currently working with their mentors to examine progress and further refine goals for career progression. The third and final phase of this programme will take place in May 2021.



Study Presentations

Bavelaar L, van der Steen J, Nicula M, Morris S, Kaasalainen S, Achterberg A, & Brazil K. (2020, Nov 4-7). Developing country-specific question prompt lists about dementia palliative care for family caregivers [Conference presentation]. GSA 2020 Annual Scientific Meeting, Online. Innovation in Aging 2020; 4(Suppl 1):

786, <https://doi.org/10.1093/geroni/igaa057.2846>

Bavelaar L, Billekens P, Geerds P, Tam M. (2020, Dec 15). In conversation with family carers: how do you do that? [Workshop]. University Network for the Care Sector Zuid-Holland - Anniversary Tour through Good Long-Term Care, Online. <https://www.youtube.com/watch?v=o2Xl5sFdMfl>

Hartigan I, Racine E, Meehan E, McKeon M, Cornally N, Brazil K, Lisiecka D, Timmons S, Fitzgerald S, Fox S, Foley T, Sweeney C, Buckle C, O Caoimh R, McGrath H. (2020). Fit for context: Co-designing a Comfort Care booklet for people with dementia [Oral presentation]. Transforming Care and Communities – Virtual 12th International Dementia Conference.

Meehan E, McKeon M, Hartigan I, Brazil K, Rabbitte M, Lisiecka D, Timmons S, Fox S, Foley T, Sweeney C, Buckley C, O Caoimh R, Fitzgerald S, Cornally N. (2020). Communication is key: ensuring effective dissemination of key messages and new knowledge from mySupport study [Oral presentation]. Transforming Care and Communities – Virtual 12th International Dementia Conference.

Van der Steen J (2020, Dec 15). Advance care planning: Evidence and complexities in proactive care planning in case of cognitive impairment [Seminar presentation]. LUMC TOP Research Seminar, MS Teams Live Event. <https://www.lumc.nl/org/pheg/research/research-s/PHEGonderzoekindeMedia/LUMCTopResearchSeminardecember2020/>

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