

mySupport

FAMILY CARER DECISION SUPPORT STUDY

Welcome to the fifth 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 educational intervention consists of a *Comfort Care Booklet* which has been adapted to each country and we are looking forwards to sharing it with family carers to inform them about end-of-life care and the care options for people living with advanced dementia.

The past 18 months have been a difficult time due to the COVID-19 pandemic, but with the vaccination of nursing home staff and residents now completed, restrictions have started to ease.

Learn more about our research

Our mySupport Study **promotional video** is now available with subtitles in all partner country languages. 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:

[The Development of a Question Prompt List to Support Family Caregivers of People with Dementia in Advance Care Planning](#)

Ms Laura Bavelaar (Netherlands)

[COVID-19 Restricted Family Access Measures in Canada; the Impact on Nursing Home Staff](#)

Dr Tamara Sussman, Ms Susan Mintzberg, and Dr Sharon Kaasalainen (Canada)

[Developing an International Public and Patient Involvement Group for Dementia Research](#)

Dr Danielle Just and Dr Emily Di Sante (Canada)

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 to see if the intervention worked and how it could be rolled out to other nursing homes in the future. This includes information about the nursing homes and the perspectives of staff and family carers. Most of the countries have now finished gathered data to understand the context of the recruited nursing homes, and in many sites family members have now been recruited to participate in the study. Some countries have also started to conduct family care conferences. These are meetings between the family and staff to discuss end-of-life care for the resident and take place after the family has been provided with the *Comfort Care Booklet*.

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Dr. Marcel Arcand describes how the “Low-Tech High Touch Care” approach for persons with advance dementia promotes dignity and comfort

A palliative approach to care is often viewed by family as a decision to let go and stop providing active treatment. Dr. Marcel Arcand, author of the Comfort Care at End-of-Life booklets, now translated and used across 9 countries, dispels this myth in a two-part video developed in collaboration with the MySupport team. In the videos, Dr. Arcand describes the features of what he calls a “low-tech high-touch” approach to care and emphasizes that family carers play a vital and active role when a palliative approach is adopted.

Symptom control, mouth care, ongoing pain assessments, comfort feeding, touch, music, attention to dignity and personalized care are examples of this approach to care for persons with advance dementia. While these activities are not medically complex, they require astute and ongoing observation and interaction.

According to Dr. Arcand, in a low-tech high-touch approach the key treatment is that of “promot[ing] dignity and finding all the ways to make the person with dementia comfortable”.

The videos are undergoing final editing and will be available to view shortly on the MySupport Website



Professor Marcel Arcand, University of Sherbrook and Centre of Aging in Québec, Canada, dedicated to family medicine in long-term care and end of life decision making for persons and families with dementia.

Scientific Journal Submissions

The Italian team recently submitted a manuscript titled “Interventions to support family caregivers of people with advanced dementia at the end of life in nursing homes: a mixed-methods systematic review”, which is currently under revision.

The Dutch team is currently finalising a manuscript about comparative work on the Comfort Care Booklets. A collaborative manuscript about the development of the Question Prompt Lists was submitted early 2021 and is currently under review.



Dr Silvia Gonella from the University of Torino successfully defended her PhD with the title "End-of-life communication in nursing homes". Congratulations, Silvia!

Study Presentations

Di Giulio, P., Gonella, S (2021, June 21). mySupport study - informazione e dialogo sulle scelte di fine vita tra infermieri e familiari nelle residenze per anziani. Presentation added to University of Torino, Italy homepage.

Cornally, N (2021, June 1). Supporting Family in End-of-life care planning for people with Advanced Dementia. Fundamental Care for Older Adults Conference, UCC, Cork, Ireland

The UK recently submitted an abstract to the 31st Alzheimer Europe Conference which focuses on how researchers have adapted their research practice to ensure the viability of the project.

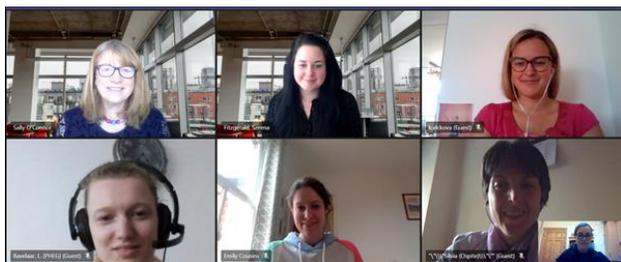
The team in Northern Ireland submitted an abstract submitted to the European Association Palliative Care conference which was accepted for a poster presentation.

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Early Career Researchers' Committee (ECRC)

The ECRC have been busy over recent months completing the mentorship programme, progressing their publication strategy and being actively involved in monthly presentations. Dr Karolína Vlčková (Czech Republic), Dr Andrew Harding (UK), and Emily Di Sante (Canada) all presented at our monthly committee meetings.



Polyvagal Theory for Career Progression and Leadership – workshop with Sally O'Connor

The mentorship programme came to an end in May with Sally O'Connor hosting the final programme workshop on "Polyvagal Theory for Career Progression and Leadership". We were also delighted to welcome back Laura Banefield from McMaster University who hosted a successful follow up workshop on "Navigating the (Confusing) World of Publishing".

We would like to thank our outgoing core committee, Danielle Just (Chair), Emily Di Sante (Vice-Chair), Laura Bavelaar (Secretary) and Maria Nicula (Social Media and Activity Officer) for their ongoing commitment and leadership over the past six months. We look forward to welcoming the new incoming core committee and new ECRC members in August.

Online communication across partner countries

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. In addition to our regular meetings we are conducting case study meetings where issues related to the intervention are discussed. This month the focus was on our experiences of recording field-notes and decision-making relating to the implementation so far.

Why don't we talk about death and dying? Dr Irene Hartigan, UCC

MySupport study is an international study that looks at education for nurses and family carers on how to navigate the difficult decisions at the end of life for a person with advanced dementia. As part of the mySupport Study a booklet provides information about advanced dementia and the difficult decisions that will be faced towards end of life and the dying process.

It is inevitable that we will all die. So why don't we talk about death or prepare for it? Do we talk about our own death and what that would look like? Far too often we shy away from conversations or hope that some medical intervention will help prolong life. Doctors and nurses encourage dialogue between patients and families however far too often this comes at a time when a family member's health deteriorates. At this point, families are trying to process several emotions and face the reality of the situation. The preparation for death and expression of grief varies across cultures and the opportunity to begin this dialogue, as part of mySupport study, can enhance the quality of the end-of-life dignity and give opportunity for a new narrative associated with death and dying. Resources are available on the mySupport website to help facilitate discussions:

<https://mysupportstudy.eu/resources/>

Also a blog by Dr Nicola Cornally talks about using the opportunity of Advance Care Planning as a Medium for Providing Care Aligned to Peoples Wishes. [Link here](#)

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