

FAMILY CARER DECISION SUPPORT STUDY

Welcome to the penultimate edition of mySupport study newsletter, mySupport study is now complete and funding expires at the end of the summer for most countries. Nonetheless, the analysis and sharing of our study findings continues. We will be busy for the summer months writing key papers for publication in scientific journals. Having enrolled 16 nursing homes across 6 countries, we have a lot of results to share with the public, policy makers and the research community. We will prepare a final newsletter at the end of the year listing the study's outputs and communications.

The pandemic led to some variation in the timelines across the six countries, however we still managed to engage families (n=93) and train nurses (n=50) across all sites. We are grateful for everyone's participant and we have learnt new ways to enhance advance care planning for people with dementia at the end of life. We would like to sincerely thank all study participants and consortium partners for their commitment to mySupport study.

KEY Events

Consortium meeting -The team were finally able to come together in Leiden University Medical Center (LUMC) on the 23rd of March 2022. The knowledge exchange meeting gave the opportunity for partners to connect and discuss work packages. The consortium meeting began with a sell-out symposium entitled 'New & Emerging Models of Advance Care Planning for Older Persons'. Read more [here](#)

MySupport Symposium at the 26th Nordic Congress of Gerontology, Denmark, several members of the consortium team presented at the mySupport study symposium on Advance Care Planning intervention aimed at enabling families to engage with nursing home staff in advanced dementia end-of-life care conversation. mySupport symposium was one of forty-four symposia with 4 abstracts from a total 100 oral presentations. Read more [here](#)

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

Cultural differences and advance care planning for residents with dementia in nursing homes– emerging considerations and recommendations from the mySupport study. Authors: Alan Connolly, Lancaster University, United Kingdom, Silvia Gonella, University of Turin, Italy, Karolina Vlckova, Center for Palliative Care, Czech Republic, Laura Bavelaar, Leiden University Medical Center, Netherlands, Nicola Cornally and Irene Hartigan, University College Cork, Republic of Ireland. **Date of Publication:** June 2022

The importance of small-scale residential care units for people with dementia in the Netherlands. Author: Marianne van Brussel, mySupport study Strategic Guiding Council member, the Netherlands
Date of Publication: April 2022

A diagnosis of 'dementia' is not enough; the type of dementia influences the window for shared decision-making. Author: Professor Suzanne Timmons, Centre for Gerontology and Rehabilitation, University College Cork
Date of Publication: March 2022

'Necessary Discussions', supporting family carers and staff in advance care planning during a COVID-19 outbreak in a care home Author: Professor Kevin Brazil, Professor of Palliative Care School of Nursing and Midwifery, Queen's University Belfast, United Kingdom. **Date of Publication:** February 2022



Consortium Meeting hosted by Leiden University Medical Centre.

After meeting monthly for over 2 years, on MS teams, the team were finally able to come together in Leiden University Medical Center (LUMC) on the 23rd of March 2022. The knowledge exchange meeting gave the opportunity for partners to connect and discuss work packages. The consortium meeting began with a sell-out symposium entitled 'New & Emerging Models of Advance Care Planning for Older Persons'. Professor Lieve Van den Block gave the keynote presentation on Advanced Care Planning (ACP) in Dementia and shared her views on the wide range of definitions of ACP and few are specific to dementia. Professor Carl May gave an interesting and theoretically driven talk about shared decision-making. Professor Peter Martin shared his experience on how communication is a vital aspect of ACP. During the comfort break, it was great to chat with our Public and Patient Involvement (PPI) panel members who represented the international Strategic Guiding Council.

Professor Dorothea Touwen spoke about self-determination for older persons with or without dementia. Professor Jenny van den Steen shared insight into a new definition of ACP based on a current international Delphi study and Prof Tamara Sussman highlighted the importance of moments and time for ACP-the naturalised ACP process emphasising the need to leverage all opportunities to inform ACP in long term care. The symposium was attended by over 100 delegates from across the globe and the team facilitated live in person, recorded and live online speakers, indicative of the hybrid/blended model of connecting that the pandemic has brought about.

The 26th Nordic Congress of Gerontology (NKG) was held in Odense Denmark on the 8th-10th June. The title of the conference was **Change and Continuity**, which was pretty apt given the changes in life that we all have experienced over the last 2 years, the COVID-19 pandemic has provided valuable new insights. mySupport symposium was one of forty-four symposia with 4 abstracts from a total 100 oral presentations. Professor Jenny T. van der Steen, Leiden University chaired the symposium session followed by Dr Nicola Cornally who presented an overview of the mySupport intervention and its adaption and implementation across 6 countries.

Our mySupport partners from University of Turin, Dr Silvia Gonella and Dr Laura Bavelaar, Leiden University, presented on strategies to tailor mySupport intervention to local characteristics and needs as well as using an educational booklet to empower nurses in Advance Care Planning conversation. Dr Irene Hartigan presented *Remote knowledge translation and exchange (KTE) strategies – engaging staff and families in the mySupport study during COVID-19* on behalf of the Irish team. The EMTReK model which is an Evidence-based Model for the transfer and exchange of Research Knowledge was developed for palliative care and this was fundamental to guiding all knowledge translation and exchange (KTE) during the implementation of the mySupport intervention. Our partners in Lancaster University, UK, Professor Nancy Preston and Dr Andrew Harding presented on the challenges with regard to implementing ACP during the COVID-19 pandemic in long term care facilities.



Dissemination Opportunities

Cornally, N. (2022). Introduction of the overview abstract- Implementation of advance care planning in dementia with nursing home staff and family caregivers during Covid-19: The six-country mySupport study. **Available at** <https://www.26nkg.dk/abstract.html> **page 62.**<https://www.26nkg.dk/abstract.html>

Silvia Gonella, S., Angaramo, M., Di Giuilio, P., (2022). Strategies to tailor the mySupport intervention to local characteristics and needs. **Available at** <https://www.26nkg.dk/abstract.html> **page 62.**

Bavelaar, L., van der Steen, J., Visser, M. (2022) Using an educational booklet to empower nurses in advance care planning conversations with family of nursing home residents with dementia. **Available at** <https://www.26nkg.dk/abstract.html> **page 62.**

Hartigan, I., Connolly, A., FitzGerald, S., Buckley, C., Foley, T., Timmons, S., Sweeney, C. Mckeon, M., Cornally, N., (2022). All Ireland Institute of Hospice and Palliative Care, Ireland. Remote knowledge translation and exchange (KTE) strategies: Engaging staff and families in the mySupport study during COVID-19. **Available at** <https://www.26nkg.dk/abstract.html> **page 62.**

Harding, A., Brazil, K., Cousins, E., De Vries, K., Doherty, J., Harrison-Dening, K., McCann, A., Preston, N., Varey, S., (2022). mySupport Group; Necessary Discussions Group. (2022). Facilitators, barriers and lessons from undertaking two Advance Care Planning implementation studies remotely & online during a global pandemic. **Available at** <https://www.26nkg.dk/abstract.html> **page 63.**

Preston, N., Brazil, K., Carter, G., Cockshott, Z., Cousins, E., Doherty, J., Finucane, A., Hanratty, B., Harrison Dening, K., McCann, A., Mitchell, G., Russell, S., Stocker, R., Varey, S. (2022). Experiences of advance care planning during the COVID-19 pandemic in long term care facilities. . **Available at** <https://www.26nkg.dk/abstract.html> **page 63.**

Connolly, A., Hartigan, I., Foley, T., Timmons, S., Sweeney, C. O’Caoimh R., FitzGerald, S., Buckley, C., Cornally, N. (2022). Improving family caregiver involvement in end-of-life care for people with dementia: The implementation of the mySupport study in nursing homes in Ireland. Sigma 6th Biennial European Conference, Dublin. Theme: Equality and Empowerment 1. **Available at** [Sigma 6th Biennial European Conference - The Circle \(sigmanursing.org\)](https://www.sigmanursing.org)

Vlckova, K, Loucka, M. (2022) Barriers and Facilitators to Implement Family Carer Decision Support Intervention Using Family Care Conferences in Nursing Homes in the Czech Republic: National Data From Mysupport Study. 12th World Research Congress of the European Association for Palliative. Palliative Medicine, 36 (1) page:40. Available at: [Abstracts from the 12th World Research Congress of the European Association for Palliative Care, 2022 \(sagepub.com\)](https://www.sagepub.com)

Participants’ Perspective

This is the second 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.

Family were comforted with the opportunity to speak the nurses about the end of life preferences for the person with dementia.

“In any end-of-life care regarding people with dementia, the wishes of the family need to be taken into consideration more, regarding quality of time versus quantity. Generally speaking, I feel that sometimes families’ wishes are overridden by medical considerations” (Family, pre-questionnaire).

The booklet was commended for several reasons.

Families said “the format of the booklet ie laid out in sections allowed them to review the information in small bites”.

Staff reported they had “received information prior to getting the booklet and the booklet provided nurses with a “hook” or starting point on how to broach this sensitive subject with family carers. Now everybody here wants the booklet. “.

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This project is funded by the EU Joint Programme – Neurodegenerative Disease Research (JPND), the largest global research initiative aimed at tackling the challenge of neurodegenerative diseases. JPND aims to increase coordinated investment between participating countries in research aimed at finding causes, developing cures, and identifying appropriate ways to care for those with neurodegenerative diseases - www.jpnd.eu

