

## Global Pandemic

The research team have taken various measures to plan mySupport study activities appropriately to meet the ongoing challenges of COVID-19 into the near future.

## Contact us

Visit [www.mysupportstudy.eu](http://www.mysupportstudy.eu) for more information. To sign-up to mySupport study eNewsletter, simply send us a request via email.

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## The aim of mySupport study

mySupport study will explore the effectiveness of the Family Carer Decision Support (FCDS) intervention. Three key objectives of mySupport study are to:

1. Adapt the Comfort Care Booklet and Question Prompt List for each country participating in the study.
2. Implement the Comfort Care Booklet with Question Prompt List in nursing homes for people with advanced dementia using Family Care Conferences or meetings.
3. Evaluate the impact of the intervention on family carers and nursing home staff.

## Activities taking place across the 6 countries include:

- Implementing the Family Carer Decision Support (FCDS) educational intervention across a minimum of two nursing homes per participating country over a 12-month period.
- Measuring the impact on family carers who received the educational intervention and nurses who delivered it.
- Creation of guidelines between the research team, voluntary advisory groups and facilitators implementing the educational intervention, so that the intervention can be replicated in the future.



This is an EU Joint Programme - Neurodegenerative Disease Research (JPND) project. The EU Joint Programme - Neurodegenerative Disease Research (JPND) is 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](http://www.jpnd.eu)

**mySupport**  
FAMILY CARER DECISION SUPPORT STUDY

**Supporting care home staff to engage in decision-making with family carers**

**SCALING UP AN EDUCATIONAL INTERVENTION**



## How is the Family Carer Decision Support (FCDS) intervention delivered?

There are three core elements to the intervention:



1. Provision of a Comfort Care Booklet to family carers. The Comfort Care Booklet describes an approach to care that focuses on optimising comfort towards, and at, the end of life, while taking into consideration the person's wishes.
2. Training of Nursing Staff. Nursing staff at all study sites will be trained on the use of the Comfort Care Booklet and the facilitation of Family Care Conferences. This training will be a merge of online and some face-to-face using social distancing.
3. Delivery of a Family Care Conference. This is a meeting between trained nursing staff and family carers. In the Family Care Conference, a trained nurse will review and discuss the contents of the Comfort Care Booklet with family carers aided by the Question Prompt List.

## mySupport study vision

As an international team of healthcare researchers and clinicians, we are working together to support healthcare staff to have end-of-life care discussions with family carers of people living with advanced dementia.

## Background

An educational resource called the Family Carer Decision Support (FCDS) intervention has been developed to assist nursing home staff in supporting family carers when they need to make difficult decisions about end-of-life care for their relative with advanced dementia. In a study conducted in the United Kingdom, the intervention was shown to reduce family carer decision-making uncertainty and to improve satisfaction with fundamental choices related to their relative's comfort and care.

## Learning from family carers' lived experiences

Public and Patient Involvement (PPI) is an important component of mySupport study. Voluntary advisory groups have been set up in each of the participating countries to co-design and develop project activities. Also, an international group known as Strategic Guiding Council has been set up.

## Our members



mySupport study is an international consortium made up of healthcare researchers and clinicians from universities and institutions. The lead institutions in each country are: Queen's University Belfast (United Kingdom), University College Cork (Republic of Ireland), McMaster University (Canada), Turin University (Italy), Leiden University Medical Center (the Netherlands), and the Center for Palliative Care (Czech Republic).

Nursing homes will be invited by leads in each member country for implementation of the Family Carer Decision Support (FCDS) intervention.

Within each of the lead institutions, Early Career Researchers are involved and encouraged to share learnings across mySupport study sites and countries.

