

Study Title: In-Touch: Implementation of a person-centered palliative care intervention to improve comfort, quality of life and social engagement of people with advanced dementia in care homes

The In-Touch Study

What is the In-Touch Intervention?

The In-Touch intervention is a non-pharmacological, palliative care intervention for people with advanced dementia who live in long-term care homes, their families/care partners, and staff. The In-Touch intervention has great potential to improve the care of residents who have advanced dementia; to promote a proactive palliative care approach among staff; and to build family-staff partnerships in shared decision-making on 'in the moment care' (Namaste Care) and future care planning (Family Carer Decision Support).

The In-Touch intervention builds on previous work that was conducted in six countries, in the *mySupport* study. The *mySupport* study (https://mysupportstudy.eu/) was an international multidisciplinary study to support family carers of persons with advanced dementia living in long-term care homes, in making complex decisions surrounding end of life care (Bavelaar et al., 2022).

The In-Touch intervention will combine two existing, complementary interventions, 1) Namaste Care, 'in the moment care' and 2) Family Carer Decision Support, planning for future needs, which includes a Comfort Care Booklet.

The In-Touch study research team will adapt, implement, and evaluate the In-Touch intervention in a large cluster randomized controlled trial in 56 care homes, in 7 countries: Ireland, United Kingdom, Italy, Poland, Portugal, Netherlands, and the Czech Republic.

How will the Care Partner Advisory Group be involved?

Members of the international Care Partner Advisory Group (CPAG) will use their experience in caring for a person with dementia to provide advice on the In-Touch intervention materials and activities.

The research team at McMaster University (in Ontario, Canada) will hold virtual meetings in English (over MS Teams) with advisory group members from all partner countries, to gather input and feedback on In-Touch intervention materials and study activities that emerge as the project progresses. In the *mySupport study*, for example, care partners were involved in activities such as reviewing study materials/new resources, helping with analysis, knowledge translation, and/or presenting and writing publications about the study findings. Care partners can choose activities that they are interested in and feel comfortable contributing to.

Meetings will occur every month and will last from 1-2 hours. We will identify 2-4 care partners and a 'research buddy' (i.e., a research team member) from each partner country to contribute to the Care Partner Advisory Group.

Questions? Please contact PPI Coordinator, McMaster University, Canada [Email] [Phone]

Reference: Bavelaar L, McCann A, Cornally N, et al. Guidance for family about comfort care in dementia: a comparison of an educational booklet adopted in six jurisdictions over a 15-year timespan. *BMC PaliatCare*. 2022; **21**(1): 76. doi:10.1186/s12904-022-00962-z