



Project CEOL-CARE (Confidence in End-Of-Life CAREgiving)

**Building confidence in End-of-Life care: A multi-professional skills-based support programme for informal caregivers to optimize palliative and end-of-life care in the home.**

Although home care at end-of-life is the wish of most Swiss people, relatively few achieve this in comparison to the European average. End-of-life care is challenging, families and informal caregivers are required to engage in complex care tasks, often in situations of dependence and clinical instability, including physical comfort care and medication management. Often, little or no training/guidance is available. This impacts informal caregiver safety and security and risks poorer outcomes overall, including crisis hospitalization. Current services lack strategic end-of-life coordination to ensure timely access to appropriate support. Gaps include limited understanding of the specific skills and environmental adaptations needed, how to optimize care priorities appropriately and to ensure individual need and context is taken into account. After the death, a poor experience of caregiving may result in poorer coping or pathological grief reaction.

Nurses provide critical investment in the lives of patients and families, promoting strategic innovations to optimize well-being and quality even in the dynamic of frailty, dying and death. Community nurses working in home care services regularly care for people with end-of-life care needs. This may also include support from specialist mobile palliative care services. Strengthening nurse collaboration between generalist and specialist care providers will assist in identifying and addressing gaps in service provision, promote a more collaborative care planning and avoid inappropriate transfer of care in crisis.

Using a participatory action approach (PAR) provided by an expert team of academics, clinicians and public and private agencies involved in informal caregiver support across the Canton de Vaud, we aim to co-design a tailored and flexible model of nurse-led informal caregiver support at end-of-life through responding to the research question:

- How can a nurse-led multi-professional innovation better support informal caregivers to optimize end-of-life care in the home?

The following objectives have been formulated:

- To develop partnerships between specialist and generalist palliative care providers to optimize quality end-of-life care
- To develop and evaluate the components of caregiver confidence in the act of end-of-life caregiving
- To identify factors in terms of informal caregiving support which may reduce risk of crisis hospitalization and enable the patient to remain at home.
- To develop partnerships between specialist and generalist palliative care providers to optimize quality end-of-life care
- To facilitate optimal bereavement and grief support mechanisms for informal caregivers
- To develop a protocol for a pilot study aimed at testing the implementation/feasibility of the proposed intervention
- To strengthen collaboration in palliative care nursing science for the development of programmatic patient and family caregiver research.

The expected result is a simple workable model of informal caregiver support which can instil confidence, safety and security for both patients and caregivers, helps to ensure people can stay at home in their end-of-life care scenario if desired and provide a template for sustainability across settings through establishing the vision and value of nursing leadership in community palliative and end-of-life care.