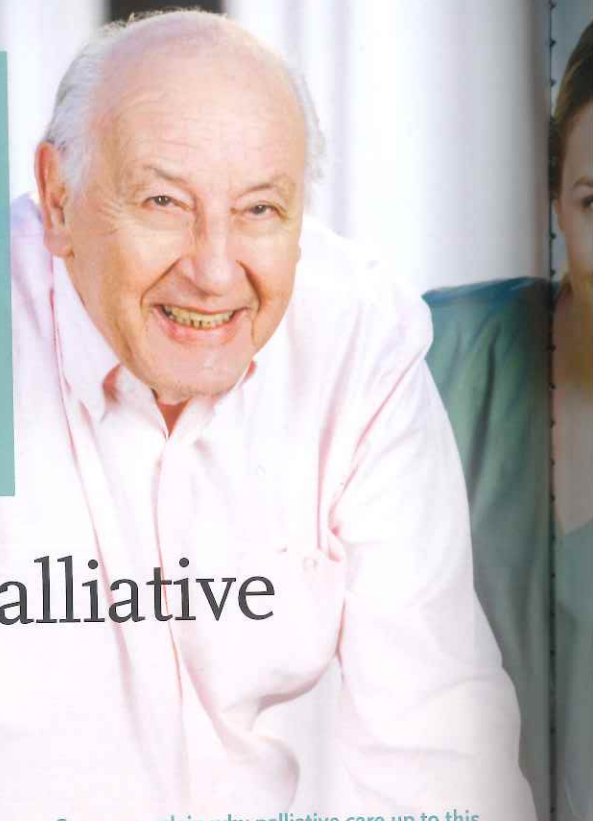


## Impact Objectives

- Better integrate palliative care into mainstream care, so as to improve the quality of life of not only terminally ill cancer patients, but also older people living with a range of potentially incapacitating diseases
- Improve the quality of life for those in long-term care facilities from not only a physical perspective, but also psychosocially and spiritually
- Create a more unified Europe in respect of the attitude and response to palliative care needs



# Changing attitudes to palliative care for older people

*Professors Lieve Van den Block and Bregje Onwuteaka-Philipsen, and Mrs Anne-Sophie Parent form part of a consortium that seeks to address the challenges associated with palliative care across Europe. Below, they describe the background to the consortium, the challenges with palliative care up to this point and why it remains a taboo subject*



From left: Professors Lieve Van den Block, Bregje Onwuteaka-Philipsen and Mrs Anne-Sophie Parent

**Can you begin by explaining the background behind the comparing the effectiveness of palliative care for older people in long-term care facilities in Europe (PACE) consortium?**

**LVdB:** PACE has been developed because of the need for palliative care research and improvement in long-term care facilities. Palliative care is still too often seen as terminal care for terminal patients. While palliative care originated from the needs of cancer patients who suffered at the very end of their lives, there is a strong consensus within the field that it also includes application much earlier in a disease trajectory and has important added value in improving quality of life (in terms of physical, psychosocial and spiritual aspects) for older people who suffer from multiple problems and conditions for a long time. PACE aims to provide answers to several international calls for recognising palliative care as a public health concern and for better integration of palliative care in mainstream care.

**Do you believe there is enough discourse on the topic of our ageing society? Are policy makers, governments and agencies doing enough to both address current problems and anticipate future issues?**

**ASP:** My answer is no, or rather that the discourse needs to change. In public discourse, population ageing is still too often presented as an economic challenge and a threat to the public purse and intergenerational fairness. The main policy reforms are aimed at containing the cost of ageing on the publicly-funded pension and social protection systems. There is a trend however, which tries to turn Europe's demographic 'challenge' into an opportunity that could create more jobs and foster economic growth in Europe through the so-called 'silver economy'.

In the field of health and long-term care, some try to find solutions to offer better care at a cheaper cost through various initiatives targeted at older persons, but much more needs to be done to give access to all. It is essential that we improve the lives of older persons with life-threatening conditions, ensure they can manage their pain, and get the psychological and emotional support they need to live and die with dignity.

**Can you explain why palliative care up to this point has had negative connotations? Why is it vital to change attitudes towards palliative care programmes?**

**BOP:** Palliative care has negative connotations for many people because they associate it with death and dying. Acknowledging that the end of life is near for somebody and that cure is no longer possible is difficult – both for individuals and in conversations between people. When talking about life-threatening disease this is often done in terms of not giving up and fighting. There can be a hesitance of care providers to discuss palliative care options with patients and their relatives because of the association with death and dying.

Palliative care programmes can only be successful if people are willing to openly and proactively think about how the time left can be spent with as much quality of life as possible. So, a shift in attitude among healthcare providers, patients and family – and more broadly society – to think about and discuss at a timely point the last phase of life (in terms of weeks, months and even years) is essential for the success of palliative care programmes.

**Why has palliative care in the past been mainly offered to cancer patients?**

**LVdB:** Palliative care grew out of the hospice tradition, which began as terminal care for cancer patients, particularly in the UK. The main reason for this is because the need of these patients was clearly high. Many suffered from severe symptoms, not only physical, but also psychosocial and





spiritual. From these needs, hospice and other palliative care services grew. However, the way these specialist services operate does not fit the disease trajectories of older people. The latter often have multiple problems and conditions, over longer periods of time, and needs that fluctuate considerably across the disease trajectory. Hence, providing palliative care to these groups of people at the right time will involve more than a culture change; it will also involve system and service changes which might take a long time – and we need evidence to be able to show how it might work.

**How do European countries differ to the rest of the world in terms of palliative care policies and programmes? Is Europe leading the way in realising the significance of this area of research and development?**

**BOP:** The extent to which palliative care policies and programmes exist in Europe depends largely on the country. There are countries where there are well developed policies and programmes in place and countries where they are absent. Traditionally, the UK has very strong national policy and programmes in palliative care. In the Quality of Death Index of 2015, published by *The Economist*, the UK is number one, followed by Australia and New Zealand. Other European countries in the top 10 are Ireland, Belgium, Germany, the Netherlands and France. Other European countries, especially East European countries, are generally lower on that list. Other rankings provide somewhat different results, but the overall picture they paint is rather similar. So, it is safe to say some European countries are leading the way, but there is not yet a unified European movement.

**Have you faced any challenges during the course of the research so far and, if so, how have you overcome them?**

**ASP:** The main obstacle we have faced is the negative connotation linked to the term 'palliative care', which is linked to end-of-life and raises fear of imminent death. I don't know if the negative connotation can be addressed while keeping the same term, or

if there is a need at some stage to find a new term to define what is proposed by PACE, i.e. palliative care that is complementary rather than a substitute to traditional care which seeks to cure the patient.

**Finally, why has the important issue of the effectiveness of palliative care in long-term care facilities (LTCFs) not been addressed until this point?**

**LVdB:** Palliative care and end-of-life care research is a relatively young research discipline. It is only in the last few decades that attention for non-cancer patients, and in particular people suffering from multiple conditions in old age, has grown.

However, death and dying, and therefore palliative care is still a taboo topic amongst professionals, carers and the general public. Providing palliative care early enough is also still an issue in cancer care and not limited to LTCFs. The problem does seem to be even larger when it comes to LTCFs, because the disease and illness trajectories of older people are often longer, more complex and less predictable.

In terms of LTCFs specifically, one problem is there is a huge variation in the key drivers for change in this sector. There are several different types of LTCFs, and different (inter) national and regional regulations influence the priorities identified in the field. One part of the work in PACE is to map these differences and key drivers for change.

## Steps to successful palliative care

*PACE – Comparing the effectiveness of palliative care for older people in nursing and care homes in Europe is a consortium intent on informing and assisting policy and decision-makers at national and European levels. The team hopes to develop specific tools and products to help policy makers to make evidence-based decisions on optimal palliative care delivery in long-term care facilities*

The World Health Organization (WHO) defines palliative care as being an approach to improving the quality of life of patients and their families who face the problems associated with life-threatening illnesses. There are many ways in which palliative care manifests, but a key focal point is preventing and relieving suffering, often by means of early identification and the effective assessment of treatment of pain and other problems. Through the provision of palliative care, individuals and their families can experience physical, psychosocial and spiritual benefits.

However, there is huge variability between countries in the development of palliative care. These differences have an obvious bearing on the outcomes for people dying in care or nursing homes, and it is therefore essential that a consensus on best practice be established. Such a consensus should naturally be evidence-based or evidence-informed to encourage the forming of it more rapidly. In addition, the fact societies across Europe are ageing, necessitates an improvement in the quality of life and the quality of dying for patients.

*It is as much about changing the culture of care homes, as it is the attitudes of individuals within them*





Members of the PACE (Comparing the effectiveness of palliative care for older people in long-term care facilities in Europe) consortium

### ASSESSING THE EFFECTS OF PALLIATIVE CARE

With these points in mind, a consortium from across Europe has been developed to tackle many of the challenges associated with palliative care. Entitled PACE, the consortium is composed of eight research institutes across six European countries. A total of four European organisations are responsible for the impact and dissemination of the findings. Together, they will perform three separate studies.

The three studies are, firstly, mapping palliative care systems in care and nursing homes across Europe. Secondly, the consortium will perform a large-scale representative study to examine quality of dying and palliative care in care and nursing homes in six European countries. Finally, PACE will study the impact of an innovative trial called 'PACE Steps to Success', which aims to improve the integration of palliative care in mainstream nursing home care.

Professor Dr Lieve Van den Block is coordinating the PACE project. 'One study investigates deceased residents in a representative sample of care and nursing homes in six countries,' explains Van den Block. 'In this, we compare countries with different healthcare systems, and with – or without – formal palliative care structures in terms of resident outcomes, quality of end-of-life care, and staff knowledge and attitudes.' From this, the team hopes to gain an understanding of which countries, systems and practices might be related to higher quality of dying, which can then be used as a basis for policy recommendations. The 'PACE Steps to Success' programme will be evaluated in a cluster randomised controlled trial. 'We will study whether and how the integration of a broad generic palliative care programme can lead to improved outcomes for patients and improved knowledge of staff, as well as

*The team hopes to gain an understanding of which countries, systems and practices might be related to higher quality of dying*

investigate its cost-effectiveness,' explains Van den Block.

### CHANGING THE CULTURE OF LONG-TERM CARE FACILITIES

While the ultimate goal of PACE is to have an impact on patients in long-term care facilities, the interventions that PACE are developing are specifically aimed at changing the attitudes, knowledge and skills of the staff that care for these patients. Although the study has not yet been completed, there has been encouragement in terms of the enthusiasm of the care staff the team have spoken with. There is, however, some potential difficulty in the staff finding the time to use the tools developed by PACE, as well as the many personnel changes that make sustainable implementation difficult.

It is as much about changing the culture of care homes, as it is the attitudes of individuals within them. Thus, a crucial element of successful implementation of the findings is to ensure the management and leading decision-makers of care homes are also enthusiastic; the changes PACE hopes to bring about must be supported from the top down. In light of this, the team plans to conduct extensive process evaluations that will enable them to measure the level of implementation, and give them ideas for improved implementation in other long-term care facilities.

## Project Insights

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