



International
Collaborative
for Best Care
for the Dying Person

Eighth Annual
Symposium

NEW PERSPECTIVES ON BEST CARE FOR THE DYING PERSON

NOVEMBER 16th 2023

Rotterdam, the Netherlands

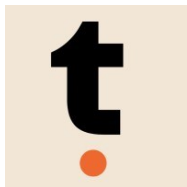


Venue:

Meet Tuesday, 23rd floor Millennium Tower

Weena 690 Rotterdam

In: [Marriott Hotel](#)



Registration:

www.bestcareforthedying.org/annual-symposium

MORNING PROGRAMME	
08:45	Registration and Coffee
Opening	
09:15	<p>Welcome and Introduction to the International Collaborative for Best Care for the Dying Person Agnes van der Heide <i>Professor of End-of-life Care and Decision Making, Erasmus MC, University Medical Center Rotterdam, the Netherlands</i></p> <p>John Ellershaw <i>Professor of Palliative Medicine, University of Liverpool, and Chair of the International Collaborative for Best Care for the Dying Person, UK</i></p>
SESSION 1 – A New Understanding of Dying in Europe Chair: Karin van der Rijt, Professor of Oncologic Palliative Care, Erasmus MC, the Netherlands	
09:25	<p>Experiences of End of Life Care: An International Study across 13 Countries Agnes van der Heide <i>Professor of Decision-Making and End of Life Care, Erasmus MC, the Netherlands</i></p>
09:45	<p>Public Engagement with Care for the Dying Person Marisa Martín-Roselló <i>Director Cudeca Hospice Foundation, Benalmádena (Malagá), Spain</i></p>
10:05	<p>An International Perspective on the Development of Volunteer Services for Care for the Dying in the Hospital Setting John Ellershaw <i>Professor of Palliative Medicine, University of Liverpool</i></p>
10:25	Q&A
10:45	Break and Poster Viewing
SESSION 2 – Best Care for the Dying Person Chair: Vilma Tripodoro, Head of the Instituto Pallium Latinoamérica, Buenos Aires, Argentina	
11:15	<p>A Core Outcome Set for Care for the Dying Person Steffen Eychmüller <i>Professor of Palliative Care, University of Bern, Switzerland</i></p>
11:35	<p>Benchmarking Care for the Dying Person Carl Johan Fürst <i>Professor of Palliative Care, University of Lund, Sweden</i></p>
11:55	<p>End-of-life Decisions: an Ethical Perspective Ghislaine van Thiel <i>Associate Professor of Medical Ethics, University Medical Center Utrecht, the Netherlands</i></p>
12:15	<p>A New Dutch Guideline for Care in the Dying Phase Lia van Zuylen <i>Professor of Clinical Palliative care, Amsterdam UMC, the Netherlands</i></p>
12:35	Q&A
12:55	Lunch and Poster Viewing

AFTERNOON PROGRAMME		
SESSION 3 – PARALLEL SESSIONS		Room
Delegates may choose any one of the following 50-minute sessions:		
14:00	1. Oral Presentations from Submitted Abstracts <i>Chairs: Ida Korfage, Erasmus MC, Rotterdam, the Netherlands, and Catarina Simões, Escola Superior Saúde Santa Maria, Lisbon, Portugal</i>	Unbea Table
	2. Design in End-of-Life Care <i>Led by Judith Rietjens and Marieke Sonneveld, Technical University Delft, the Netherlands</i>	The Corner
	3. Optimizing Medication Management <i>Led by Eric Geijteman, Erasmus MC, Rotterdam, the Netherlands, and Christel Hedman, University of Stockholm, Sweden</i>	Crea Table
	4. De Nieuwe Richtlijn Zorg in de Stervensfase: de Praktijk aan Zet <i>Led by Lia van Zuylen, Amsterdam UMC, the Netherlands, and Jet van Esch, Erasmus MC, Rotterdam, the Netherlands</i>	Unforge Table (In Dutch)
14:50	Five Minute Break to Change Sessions	
SESSION 4 – PARALLEL SESSIONS		Room
Delegates may choose any one of the following 50-minute sessions:		
14:55	5. Oral Presentations from Submitted Abstracts <i>Chairs: John Ellershaw, University of Liverpool, UK, and Catarina Simões, Escola Superior Saúde Santa Maria, Lisbon, Portugal</i>	Unbea Table
	6. End-of-life Care during the Pandemic: Lessons Learned <i>Led by Ida Korfage, Erasmus MC, Rotterdam, the Netherlands, and Stephen Mason, University of Liverpool, UK</i>	The Corner
	7. Mouth Care in the Last Phase of Life <i>Led by Grethe Skorpen Iversen, Haukeland Universitetssjukehus, Bergen, Norway, and Arianne Stoppelenburg, Erasmus MC, Rotterdam, the Netherlands</i>	Crea Table
	8. Het Zorgpad Stervensfase: van Goed naar Beter <i>Led by Marlène Middelburg, IKNL, and Karin van der Rijt, Erasmus MC, the Netherlands</i>	Unforge Table (In Dutch)
15:45	Break and Poster Viewing	
SESSION 5 – Next steps in Care of the Dying		Room
16:15	Panel Discussion: Volunteerism in Palliative Care in the Netherlands	Unbea Table
16:45	Reflections on the Day, Including Prizes for Oral and Poster Presentations <i>Agnes van der Heide, John Ellershaw</i>	
17:00	CLOSE	

ABSTRACTS

SESSION 1 – A New Understanding of Dying in Europe

Experiences of End of Life Care: An International Study across 13 Countries - Agnes van der Heide

Adequately addressing the needs of patients at the end of life and their loved ones is crucial to avoid unnecessary suffering and optimise quality of life. The iLIVE project aimed to increase our understanding of the experience of dying in different settings and cultures around the world. We conducted an international questionnaire cohort study among patients with an estimated life expectancy of 6 months or less. Over 1400 patients and 600 relatives were included. Study participants were asked to fill in a questionnaire, at baseline and after 4 weeks. If a patient died within 6 months of follow-up, the relative was asked to complete a post-bereavement questionnaire. Add-on studies focused on the role of volunteers, medication management, measuring outcomes, benchmarking and public engagement. Some of the main findings of the iLIVE project and differences between subgroups based on gender, age and cultural subgroups will be discussed.

Public Engagement with Care for the Dying Person - Marisa Martín-Roselló

Talking about death and dying is a taboo yet in most societies, but being open about end of life would be beneficial, especially for those facing this moment or for their relatives. In fact, over 70% of palliative care patients would like death to be more openly discussed in society, the percentage being higher among patients living alone than for those living with a partner. These are preliminary results from the iLIVE project.

A scoping review has been conducted to identify factors influencing community engagement, categorized into: Public health and community involvement; Community attitudes towards palliative care, death and end of life preferences; Importance of volunteers in community; and Compassionate communities. The conclusion of this review is that the societal awareness must be a facilitated process to catalyse public engagement efforts. National policy initiatives and regional system support provide legitimacy and focus is essential for funding. The first step is to know the society, channeled through health professionals connecting their assistance focus with community resources.

An International Perspective on the Development of Volunteer Services for Care for the Dying in the Hospital Setting - John Ellershaw

The volunteer study that was part of the iLIVE project aimed to develop and evaluate an international volunteer training programme to support patients dying in the hospital and their families. It has been conducted across five countries: Spain, Norway, Slovenia, the Netherlands and England, and is the first international study in the domain of volunteering in palliative care within acute hospitals. We developed a European Core Curriculum (ECC) to support the implementation of hospital end-of-life-care volunteer services; examined the impact of the volunteer services on patient distress and quality of life; explored perceptions of volunteers and healthcare professionals, towards the newly established volunteer services; and identified facilitators and barriers to implementation of hospital end of life care volunteer services.

We recruited 105 patients: 58 control group/47 intervention group. Results of the qualitative and quantitative research undertaken will be presented.

ABSTRACTS

SESSION 2 – Best Care for the Dying Person

A Core Outcome Set for Care for the Dying Person - Steffen Eychmüller

One of the aims of the iLIVE project was to create a Core Outcome Set (COS) for best care for the dying patient, involving key stakeholders at an international level: clinicians and researchers in palliative care, bereaved family members, and patient representatives. In an international Delphi study with more than 450 participants from 20 countries we reached consensus on a preliminary list of 13 outcomes. A final online consensus meeting with 31 participants resulted in a 14-item COS. These results will be critically reflected in the presentation.

Benchmarking Care for the Dying Person - Carl Johan Fürst

Quality assurance is a core aspect of modern health care. Quality measures are often described as structure (resources: e.g. beds, staff, medicine), process (activities: e.g. number of pain assessments, home visits) and results (outcomes: e.g. symptom reduction, increased quality of life). There are several initiatives within palliative care to use such measures for follow up of a specific unit and/or to benchmark with other similar services, e.g. in the UK, where a system of national, biannual audits is in place, and Sweden, which has a national, but voluntary registry. The Swedish Register of Palliative Care was designed to measure quality of the dying including the three perspectives mentioned above, with the three-fold aim of quality assurance, quality improvement and research. A translation and cultural adaptation of its post-mortem questionnaire was performed and included in the iLIVE cohort study. The aim was to evaluate quality of dying in a large cohort of European and Argentinian patients. Some preliminary results from this study will be presented and shown as a first possible step in designing an international register for palliative care.

End-of-life Decisions: an Ethical Perspective - Ghislaine van Thiel

End-of-life decision-making comes with ethical questions and dilemmas. Among these are the rights, roles and responsibilities of patients and healthcare professionals in the process of decision-making. The Netherlands has seen a rise in continuous palliative sedation and euthanasia over the past decades. There are multiple reasons for this increase. In this contribution, the changing role of patients and families in decision-making will be highlighted. Recent research on the practice of continuous palliative sedation and euthanasia will be presented, showing that the traditional emphasis in decision-making on a medical professional assessment of suffering and patient autonomy is fading. Instead, the personal values and experiences of patients and families gained influence. The changing perspective on decision-making at the end of life has implications for the role and responsibilities of healthcare professionals and raises questions concerning the applicability of current regulations and guidelines in the delivery of high-quality care at the end of life.

A New Dutch Guideline for Care in the Dying Phase - Lia van Zuylen

The development of the first Dutch guideline on Care in Dying Phase, issued in 2010, did not meet current standards for methodological quality. Moreover, there were new publications and sharpened perspectives on culturally sensitive and person-centered communication around the dying phase. Therefore, a new guideline was inevitable. A guideline committee was formed whose members were mandated from various scientific, professional and patient associations. The NICE-guideline on Care of dying adults in the last days of life of 2015 was used as a starting point. The committee met for the first time in 2021 and the guideline was finalized in 2023. It is intended for all healthcare providers involved in the care of adults with a life expectancy of days (max. 7 days). The guideline consists of modules that all start with a main question leading to recommendations supported by literature and practical experience. A systematic literature review was conducted for the modules on: marking the dying phase, death rattle (prevention and treatment), pain, and oxygen and opioids for dyspnea. The guideline has been thoroughly revised, resulting in a clear and practical guideline. Marking of the dying phase and communication with patient and relatives occupy a prominent place.

ABSTRACTS

SESSION 3 – PARALLEL SESSIONS

Oral Presentations from Submitted Abstracts

14:00 *Grethe Skorpen Iversen RN, Haukeland University Hospital, Norway*

Benefits in care of the dying from implementing a bedside clinical document - results from annual reporting

14:12 *Kate Dreyer RN, Liverpool University Hospitals NHS Foundation Trust, UK*

The IMPaCT of an innovative, joined up approach to providing palliative care

14:24 *Dr Anne Leyland, University of Liverpool, UK*

Student midwives' lived experiences of caring for bereaved parents following perinatal loss using actor-based simulation: A phenomenological study

14:36 *Dr Gabriel Goldraj, Hospital Privado, Argentina*

Attitudes towards euthanasia among Argentines with serious illnesses and limited life expectancy

Design in End-of-Life Care - Judith Rietjens, Marieke Sonneveld

The aims of this workshop are to give some insight in possible contribution of design to the quality of end-of-life care and to get hands-on experiences with design tools and techniques. The different aspects of the workshop will be illustrated through a case of advance care planning. The participants will be invited to engage in design practices.

Optimizing Medication Management - Eric Geijteman, Christel Hedman

Patients in the last phase of life often use many medications. These may be medications started at an earlier stage for treating or preventing (chronic) diseases. In the last phase of life, changes occur that make it necessary to reconsider the use of these medications. In clinical practice, such reconsideration is rare. In the workshop, we will discuss current practices of medication use by patients in the last phase of life. In addition, we will look at tools to optimise medication use in this phase of life.

De Nieuwe Richtlijn Zorg in de Stervensfase: de Praktijk aan Zet - Lia van Zuylen, Jet van Esch

In deze workshop wordt nader ingegaan op de vertaling van de nieuwe richtlijn naar de praktijk van de zorg in verschillende settings. Daarbij wordt in overleg met de deelnemers aandacht besteed aan mogelijke knelpunten, zoals diversiteit en laaggeletterdheid, zingeving en spiritualiteit, zorg voor de zorgenden, markeren en reutelen.

ABSTRACTS

SESSION 4 – PARALLEL SESSIONS

Oral Presentations from Submitted Abstracts

14:55 *Dr Barbara Hastie, Indiana University, USA*

Global Call-to-Action: Reducing inequities in palliative and end of life care by improving essential medicines consumption

15:07 *Kate Baxter and Lisa McVey, Liverpool University Hospitals NHS Foundation Trust, UK*

"One chance" - SWAN end of life and bereavement care model

15:19 *Nina Elisabeth Hjorth, Haukeland University Hospital, Norway*

"It was so unpredictable, I had difficulties giving advice and support."
Experiences providing end-of-life care during the COVID-19 pandemic

15:31 *Dr Anne Leyland, University of Liverpool, UK*

iLIVE Volunteer Study: Impact of an end of life care volunteer service on patient distress and quality of life

End-of-life Care during the COVID-19 Pandemic: Lessons Learned - Ida Korfage, Stephen Mason

During the COVID-19 outbreak restricting measures may have affected the provision of good end-of-life care for patients with and without COVID-19. In the CO-LIVE study, in the Netherlands focus group discussions have been conducted with stakeholders about lessons learned. During the workshop, the main resulting suggestions will be discussed and plans for next steps will be made.

Mouth Care in the Last Phase of Life - Grethe Skorpen Iversen, Arianne Stoppelenburg

This workshop focuses on mouth care at the end of life and the symptom of a dry mouth. The prevention and treatment of dry mouth are important but understudied topics in end-of-life care. An ongoing study on the effect of drug treatment (pilocarpine) and non-drug treatment (a nursing education program) will be presented. The workshop participants are invited to discuss their experiences with and views on treatment and the use of mouth care guidelines in palliative and end-of-life care practice.

Het Zorgpad Stervensfase: van Goed naar Beter - Marlène Middelburg, Karin van der Rijt

In Nederland wordt het Zorgpad Stervensfase gebruikt om de zorg voor patiënten die stervende zijn zo optimaal mogelijk te geven. Het Zorgpad biedt zorgverleners de structuur om de zorg voor patiënten, maar ook voor hun naasten, op een praktische manier te organiseren. Sinds de introductie van het Zorgpad Stervensfase heeft het papieren patiëntendossier plaats gemaakt voor

een elektronische variant. Daarbij is er veel discussie over registratielast in de zorg. Daarnaast leidt de nieuwe multidisciplinaire richtlijn voor de zorg in de stervensfase tot de vraag of de huidige versie van het Zorgpad Stervensfase aangepast moet worden om te voldoen aan de eisen en gebruiken van deze tijd. Tijdens de workshop gaan we met de deelnemers in overleg over de huidige versie van het Zorgpad Stervensfase: in hoeverre voldoet het Zorgpad aan de eisen van deze tijd en wat zou er eventueel aangepast moeten worden om de zorg in de stervensfase, ongeacht de plaats van zorg, verder te optimaliseren.

ABSTRACTS

SESSION 5 – Next steps in Care of the Dying

Panel Discussion: Volunteerism in Palliative Care in the Netherlands

Volunteers and healthcare staff working in hospice facilities and hospital palliative care in the Netherlands will reflect on the day and on current and future developments in volunteerism in palliative care