

End of Life Care

Current Awareness Bulletin

April 2026

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Dorothy House Palliative Care Research Conference 2026

Thursday 4th June | Dorothy House Hospice, Winsley | 09:30 – 16:00

We're delighted to invite you to our second collaborative Palliative Care Research Conference, hosted at Dorothy House Hospice in Winsley. This event brings together leading researchers and practitioners to share the latest insights, innovations, and best practices in residential and community settings within palliative care.

Why attend?

- Keynote talks from experts in the field
- Poster presentations and oral abstracts
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- Free parking & lunch provided!

Tickets:

Early Bird: **£70 until 17th April**

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Book your ticket today and secure your place at

<https://www.dorothyhouse.org.uk/palliative-care-research-conference/>

Call for Abstracts:

Submit your abstract for poster and oral presentation consideration by **Friday 27 February 2026**. Email completed forms to research@dorothyhouse-hospice.org.uk

Revealing the hidden harms in end-of-life care: a mixed-methods characterisation of reported safety incidents involving injectable symptom control medication.

Hope I. *British Journal of General Practice* 2026;76(764):e234-e243

Many patients dying in the community are prescribed injectable medications and are vulnerable to unsafe care. Developing safer and effective healthcare systems requires learning from patient safety incidents, including those resulting in no harm or near misses, however, health systems typically, must prioritise learning from harmful incidents because of resource constraints and are at risk of missing key learning.

Family members' experiences of end-of-life care in the home: a systematic review and qualitative content analysis.

Walker W. *British Journal of Community Nursing* 2026;31(3):128-140.

In recent years, healthcare policy and reform in England has advocated for community care services that enable people to live well and die well at home. This article is a systematic review that sought to determine the characteristics of a positive experience of home-based, end-of-life care, as perceived by family members.

Key Factors for Quality End-of-Life Care for People With Intellectual Disabilities. A Critical Interpretive Synthesis Review Using a 'Best-Fit' Framework Approach.

Haigh M. *Journal of Applied Research in Intellectual Disabilities* 2026;39(2):e70208

The aim of this review was to develop a theoretical framework to guide understanding of the key factors in quality end-of-life care for people with intellectual disabilities. 40 papers were selected for inclusion in the synthesis. From this, a new theoretical framework was developed comprising three themes—'a personal approach to care', 'an involved network' and 'an enabling infrastructure'.

Nurses' experiences of supporting children whose parent has a terminal illness in a palliative care setting.

Murray S. *British Journal of Nursing* 2026;35(5):278-283

Research indicates that approximately 2.2% of children in Ireland are bereaved through the loss of a parent. The death of a parent is one of the most frightening and shocking events a child must endure. The study aimed to explore nurses' experiences of supporting children whose parent has a terminal illness in a specialist palliative care setting.]

1. Assessing PA Student Interest in Hospice and Palliative Medicine

Authors: Baldeo, Ryan and Broder, Rachael

Publication Date: 2026

Journal: The American Journal of Hospice & Palliative Care , pp. 10499091261441595

Abstract: Objectives While hospice and palliative medicine (HPM) is a critical and growing field, Physician Associates (PAs) are underrepresented. This study sought to assess PA student interest in HPM and identify strategies to increase engagement with the Physician Associates in Hospice and Palliative Medicine (PAHPM) organization. Methods A cross-sectional online survey, pre-tested by subject matter experts, was distributed to PA students via PAHPM's email and social media. The survey assessed attitudes toward HPM and identified barriers to organizational involvement. Results Lack of awareness was the primary barrier to involvement (75.8%). Students expressed interest in educational resources (63.6%), job opportunities (57.6%), and mentorship (51.5%). Most respondents (81.8%) do not currently follow PAHPM on social media, but 72.7% indicated they would follow an Instagram account. Conclusions Results suggest that increasing PAHPM's visibility through targeted marketing and social media may support student engagement. Future research is needed to determine if these strategies effectively translate into long-term HPM workforce growth.

2. Development and Validation of the End-of-Life Assessment Tool for Advanced Dementia: A Multi Method Study

Authors: Bourke, Carolyn; Chenoweth, Lynn; Georgousopoulou, Ekavi and Williams, Anna

Publication Date: 2026

Journal: Journal of Advanced Nursing 82(5), pp. 5430–5443

Abstract: Aims: To develop and validate the End-of-Life Care Assessment Tool for Dementia (EoLC-ATD).; Design: A methodological study with multiple phases.; Methods: Five sub-studies comprising: a review of 90 validated dementia measures to compile an item bank of advanced dementia symptoms; focus groups with registered nurses on advanced dementia symptom identification and relevance of item bank inclusions; Delphi surveys with dementia experts seeking consensus on the EoLC-ATD constructs and items; pilot testing of the EoLC-ATD; and field testing of the EoLC-ATD in persons with dementia.; Results: The item-bank included 180 symptoms, most of which focus group nurses (n = 17) identified as occurring in advanced dementia. Delphi surveys with dementia experts (n = 31) achieved 70% consensus for 25 of 26 EoLC-ATD items. Pilot testing of the EoLC-ATD by two nurses in eight persons with dementia showed good agreement for six constructs (Cohen's Kappa 0.856-0.927) and 26 items (Cronbach's alpha 77.0). An 'other symptom' item was included following RN recommendation. The 27-item EoLC-ATD field tested by 17 nurses in persons with dementia (n = 113) accurately identified advanced dementia symptoms (Cronbach's alpha 77.0, $p < 0.001$). Mortality at 180 days after baseline EoLC-ATD was significant ($p < 0.001$, area under the ROC curve $p = 0.769$).; Conclusion: The EoLC-ATD accurately and reliably identified symptoms of advanced dementia.; Implications for the Profession And/or Patient Care: The EoLC-ATD provides registered nurses with a single measure of advanced dementia symptoms that will help in identifying symptom-responsive palliative care requirements.; Impact: The EoLC-ATD will address the current lack of a validated dementia symptom measure for use by aged care home registered nurses to identify unique palliative and end-of-life care needs according to presenting symptoms in persons living with advanced dementia.; Reporting Method: STROBE Statement for cohort and mixed methods studies.; Patient or Public

Contribution: An eight-member Expert Advisory Group, which provided guidance and advice throughout the study, was composed of three carers of persons living with dementia, two dementia care clinicians, a dementia care clinical educator, and two dementia clinician researchers. (© 2025 The Author(s). Journal of Advanced Nursing published by John Wiley & Sons Ltd.)

3. Non-Pharmacologic Modalities in Hospice Care: The Use of a Rubik's Cube for Anxiety and Depression: A Case Study

Authors: Brecher, David B. and Johnson, David Anthony

Publication Date: 2026

Journal: American Journal of Hospice & Palliative Medicine 43(6), pp. 689–691

Abstract: Psychological issues, especially anxiety and depression, are commonly seen in patients receiving Hospice care. In this case study we report on a 72 year-old male Veteran with metastatic hepatic carcinoma who has been placed in a Veterans Affairs Community Living Center (CLC) for end-of-life care. His flat affect was initially addressed by the Hospice team with psychiatric support and medication. Although suicidal ideation was not present, the Veteran did not want to leave his room or interact with others, and unfortunately, medication, natural light, massage and music were not effective in minimizing his symptoms. Our chaplain offered spiritual support and demonstrated his use of a Rubik's Cube in the hope of reducing the Veteran's stress. The Veteran was fascinated with the Rubik's Cube and the experience helped him become more interactive with staff and fellow patients. Can a Rubik's Cube be another non-pharmacological treatment option?

4. Students' perceptions of preparedness for delivering palliative and end-of-life care as they transition to registered nurse

Authors: Brown, Michelle;Shepherd, Helen;Mortimore, Gerri;Brannigan, Chris and Foreman, Dawn

Publication Date: 2026

Journal: British Journal of Nursing 35(7), pp. 370–378

Abstract: Background: Ensuring that nurses are prepared for the delivery of palliative care is essential to the provision of high-quality palliative and end-of-life care. Education plays a key role in the preparation but may encompass more than skills competence. Aim: To understand student nurses' perceptions of their preparation and experiences of delivering palliative and end-of-life care as they complete their BSc Adult Nursing pre-registration programme. Methods: Interpretative phenomenological analysis was used to explore student nurses' perceptions of delivering palliative and end-of-life care. Four in-depth interviews were conducted over Microsoft Teams. All participants were third-year nursing students at the end of their nursing programme. Findings: Participants described feelings of 'shock' and 'backlash' in caring for patients in the palliative and end-of-life stages of illness. Greater theoretical preparation and timing of preparation would have been helpful. Processes and practical tasks

acted as 'comfort blankets' and 'buffers' against the emotional distress. Perceived support is fundamental for student wellbeing. Conclusion: Students who feel anxious and ill prepared may experience emotional fatigue and burnout as they transition to newly qualified nurse.

5. Improving general practitioner involvement in care home End-of-Life care. A systematic literature review and narrative synthesis

Authors: Browne, Susannah; Kelly, Michael P.; Bowers, Ben; Kuhn, Isla; Duschinsky, Robbie; Daniels, Charles and Barclay, Stephen

Publication Date: 2026

Journal: BJGP Open

Abstract: Background: General Practitioners (GPs) are lead clinicians for palliative and end-of-life care (PEoLC) in residential aged care. Care home residents can experience uncontrolled symptoms, avoidable hospitalisations and difficult deaths at end of life. The evidence about improving GP's delivery PEoLC in care homes is limited.; Aim: Systematic review and synthesis about interventions to improve GP-led PEoLC in care homes.; Design & Setting: Systematic review and thematic narrative synthesis of peer-reviewed studies evaluating interventions to improve GP PEoLC care homes.; Method: Seven databases and grey literature searched to October 2024 using domain terms: GP, Care Homes, and PEoLC. Studies were appraised using Gough's Weight of Evidence Framework. The review followed PRISMA guidelines and was registered with PROSPERO: CRD42021254141.; Results: From 5936 titles, 35 studies were included. Eight papers reported interventions. The robustness of quantitative approaches was weak, limiting external validity and clinical generalizability. Nevertheless the following interventions proved promising: Education in PEoLC ii) Specialist palliative care involvement iii) Regular multidisciplinary palliative care meetings Thematic analysis of qualitative data identified how and why interventions worked: education increased advance care planning and staff confidence; specialist nurse support enhanced symptom management and reduced hospitalisations; and multidisciplinary rounds improved quality of deaths. Heterogeneity of approach, small sample sizes, unclear clinical population and GP involvement were a challenge for data synthesis.; Conclusion: Research on the role of GPs in care home PEOLC remains underdeveloped. Findings identified promising improvement strategies and highlighted the challenges for service improvement initiatives. There is real potential for improving the quality of GP PEoLC in care homes. (Copyright © 2026, The Authors.)

6. The professional guest: Ethical challenges in home-based end-of-life care among interprofessional teams

Authors: Halevi Hochwald, Inbal; Yakov, Gila; Weiss, Moran; Inchi, Liron; Mayan, Inbal and Sabar, Ron

Publication Date: 2026

Journal: Nursing Ethics , pp. 9697330261437250

Abstract: Background Home-based end-of-life palliative care presents unique ethical challenges that differ fundamentally from those in institutional settings. Healthcare professionals navigate the complex role of being both clinical experts and guests in patients' domestic environments, operating in a context where professional authority is continuously negotiated rather than institutionally established. Research aim This study examines the ethical tensions healthcare professionals encounter in home-based end-of-life palliative care and explores the strategies they employ to balance and negotiate competing ethical values within patient-family relationships. Research design A qualitative study using thematic content analysis conducted through focus groups and semi-structured interviews. Participants and research context Thirty-three multidisciplinary healthcare professionals from Israeli home-based hospice care participated, all employed by a national organization specializing in home-based medical services. Data was collected through three profession-specific focus groups (physicians, nurses, social workers) and nine semi-structured interviews with organizational leaders. Ethical considerations The study was approved by the Institutional Review Board. All participants provided written informed consent, were assured confidentiality and anonymity, and informed of their right to withdraw without consequences. Findings Two interrelated themes were identified. "From Guest to Clinician" describes how professionals balance clinical authority with domestic sovereignty, manage involuntary exposure to private patient information, and develop "protective witnessing," a deliberate ethical practice of selective attention preserving patient dignity. "Distributed Responsibility in Multi-Stakeholder Care" reveals the paradox of accountability without control: professionals bear clinical responsibility without institutional oversight while working alongside family members as untrained care partners with competing priorities. Conclusions Home-based palliative care places professionals at the intersection of clinical responsibility and domestic sovereignty, a position for which existing frameworks offer insufficient guidance. Addressing these structural and relational challenges requires both individual-level preparation, including training in ethical decision-making in low-control environments, and systemic policy reform.

7. From Cultural Diversity to Cultural Humility: Reflections on Internationally Educated Nurses in End-of-Life Care

Authors: Han, Bing; Qi, Mengxia and Cao, Chunju

Publication Date: 2026

Journal: Journal of Advanced Nursing 82(5), pp. 5572–5573

8. Examining Education Models for Clinical Staff Working with People with Intellectual and Developmental Disabilities in Hospice and Palliative Care: A Narrative Literature Review

Authors: Moore, Caitlyn M.

Publication Date: 2026

Journal: American Journal of Hospice & Palliative Medicine 43(5), pp. 553–563

Abstract: Background: Education and training are essential for providing quality hospice and

palliative care (HAPC). Despite individuals with intellectual and developmental disabilities (IDD) living longer with serious illness, healthcare professionals report inadequate training in this area. Additionally, IDD specialists consistently express discomfort and limited knowledge regarding HAPC. Objective: This narrative review evaluates existing education and training models for hospice and palliative care (HAPC) professionals working with individuals with IDD, emphasizing the reciprocal educational needs between these two specialties. Methods: A comprehensive literature search was conducted in March 2024 across multiple databases, including Embase, PubMed, and CINAHL, using terms related to IDD, training, and palliative care. Inclusion and exclusion criteria were applied, resulting in seven relevant studies providing insight into educational interventions for IDD and palliative care professionals. Results: Findings indicate that while several studies demonstrate positive outcomes regarding knowledge, self-efficacy, and satisfaction among participants, there is a lack of standardized training and patient-centered metrics. Existing interventions largely focused on improving the knowledge of IDD staff regarding HAPC, with limited attention given to educating HAPC professionals on the nuances and complexities needs of people with IDD. Conclusion: This review underscores the importance of developing and implementing evidence-based and standardized training programs that encompass the needs of both HAPC and IDD specialists. Future research should prioritize inclusive educational frameworks that involve individuals with IDD and their families in the development process. Attention to exploring metrics beyond self-reported outcomes to enhance the quality of HAPC provided to this vulnerable population should be prioritized.

9. Palliative and end-of-life care from an education lens. An international systematic review of undergraduate medical and nursing students' knowledge, perceptions, and orientation towards palliative and end-of-life care

Authors: Natuhwera, Germanus;Ellis, Peter and Namisango, Eve

Publication Date: 2026

Journal: Palliative Care & Social Practice 20, pp. 1–30

Abstract: Introduction: Nursing and medical schools and universities are increasingly integrating palliative and end-of-life care education in their curricula. However, research on the impacts of training and education on future nurses and physicians remains sparse. Aim of the review: The aim of this review was to systematically appraise existing research evidence on undergraduate nursing and medical students' knowledge, perception, and orientation towards palliative and end-of-life care. Methods: This international systematic review was conducted between April and May 2021 and was updated in May 2024. A systematic search was conducted in four databases: Hinari 'Research4Life', Cumulated Index to Nursing and Allied Health Literature (CINAHL), Google scholar and PubMed. Methodological quality of the included studies was assessed using the Mixed-Methods Appraisal Tool. A data extraction sheet was developed for this review. A convergent integrated approach to mixed-method data synthesis and integration was used to analyse and report the evidence. Braun and Clarke's inductive and deductive thematic analysis approach was used to identify main themes. Results: A total of 64 peer-reviewed research articles met eligibility criteria and were included in the review. Of the 64 eligible research articles, 34 employed a descriptive quantitative cross-sectional design, 11 studies were qualitative, 14 used a quantitative non-randomised design

and 5 were mixed methods. The review identified three major thematic categories: (1) students' knowledge of palliative and end-of-life care, (2) attitude, perception and orientation towards palliative and end-of-life care and (3) predictors of knowledge, orientation, attitude and perception towards palliative and end-of-life care. Conclusion: Findings suggest inadequacy and variability in knowledge levels, self-efficacy, willingness, perception and orientation towards palliative care and end-of-life care. Surprisingly, this is common across studies, including those from high-resource countries. Inadequate, limited and/or inconsistent curricula and training content about palliative and end-of-life care is a common theme in the literature. Plain language summary: A systematic review examining international published research on undergraduate nursing and medical students' understanding, views and attitudes towards caring for people with life-limiting illness Why was the study done? Globally, many nursing and medical training schools and universities are now integrating teaching and training on how to care for people facing life-limiting illnesses in their curricula. However, the distribution and nature of research evidence about future nurses' and medical doctors' understanding, views, attitudes, willingness and ability to care for those facing serious illness and the dying remains under reported. What did the researchers do? The researchers searched four online databases which store research publications on healthcare. These were-: Hinari 'Research4Life', CINAHL, Google scholar, and PubMed. The search was conducted between April and May 2021 and was updated in May 2024. Retrieved articles were screened against an established eligibility criterion and were assessed for scientific quality using the Mixed Methods Appraisal Tool (MMAT). A sheet was designed for data extraction. Data extracted from eligible studies were analysed, combined and reported using main topics derived both from the study aims and the data. What did the researchers find? 64 research articles were found eligible for inclusion. Of these, 34 reported findings using statistics, 11 studies reported findings in narrative form, 14 involved experimentation, and four used mixed methods. Three main themes emerged-: student' views and understanding, students' attitudes and orientation, and factors that influence students' understanding and attitudes regarding caring for people with life-limiting illness. What do the findings mean? Findings suggest inadequacy and variability in views and understanding, perceived ability, willingness, and attitudes towards working with people with life-limiting illnesses. Inadequate teaching and training and lack of and/or limited real-life and problem-based learning opportunities, particularly interaction with the dying is a common finding in this study.

10. The Health Service Model for Promoting Good Death in Critically Ill End-of-Life Patients in the Emergency Department: A Qualitative Study

Authors: Sirivarawuth, Tidarat;Utriyaprasit, Ketsarin;Ratinthorn, Ameporn;Tankumpuan, Thitipong and Viwatwongkasem, Chukiat

Publication Date: 2026

Journal: Omega: Journal of Death & Dying 93(1), pp. 372–396

Abstract: Good death is one of the important outcomes of end-of-life care service delivery. The initial management of critically ill patients in the Emergency Department (ED) for promoting good death often challenging since it requires a focus on human dignity and equity at the end of life. A qualitative approach was used included eight bereaved family members who loss of their loved one in the ED and 25 emergency staff, including 11 emergency

physicians and 14 emergency nurses of a super tertiary hospital in Thailand. Semi-structured, face-to-face interviews were conducted from February to August 2021. All the interviews were transcribed verbatim for content analysis. The result identified four distinct scenarios and seven core themes of end-of-life patient characteristics in the ED. To promote a good death in the ED, health care provider should consider the unique service deliver for each critically end-of-life patients and their family members.

11. End-of-Life Care for Patients with Dementia in the Emergency Department-Reflexive Thematic Analysis of the Perspective of Health Care Professionals

Authors: Vieira Silva, Sara; Bertão, Manuela; Teixeira, Carla and Antunes, Bárbara

Publication Date: 2026

Journal: Journal of Palliative Medicine , pp. 10966218261441207

Abstract: Background: Patients with dementia at the end-of-life frequently visit the emergency department. These visits can be distressing for patients and families and challenging for staff.; Aim: To explore the perspectives of emergency department health care professionals about end-of-life care for patients with dementia in the emergency department.; Design: Qualitative study using semi-structured focus groups interviews (n = 23). Interviews took place in-person after recruitment via a contact person and were transcribed verbatim. Reflexive thematic analysis was used.; Setting/participants: Physicians, nurses, and health care assistants who regularly work at the emergency department of a tertiary hospital.; Results: Participants' views on end-of-life care for patients with dementia in the emergency department produced five main themes: (1) the cultural context and perceived place of patients with dementia in the emergency department and in society; (2) the person with dementia-their dignity and multidimensional needs; (3) end-of-life care in the emergency department-managing uncertainty, setting goals, and meeting specific care needs; (4) conditions for supporting the palliative care needs of patients with dementia at the end of life in the emergency department; and (5) ethics and moral distress of health professionals in caring for patients with dementia at the end of life in the emergency department.; Conclusions: Health care professionals identify strengthening dementia awareness, implementing structured training programs, and improving the physical environment and care models within emergency departments as key priorities for practice.

12. "Family-as-Root" and "Family-Centeredness" in hospice care: a concept analysis and implications for nursing practice

Authors: Yan, Chao; Ji, Ai and Li, Yonghong

Publication Date: 2026

Journal: BMC Palliative Care

Sources Used:

The following databases are searched on a regular basis in the development of this bulletin:
British Nursing Index, Cinahl, Medline along with a number of other sources

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