This monthly Current Awareness Bulletin is produced by the Library, Musgrove Park Academy to provide staff with a range of resources focussing on end of life care. It includes recently published guidelines and research articles, news and policy items.

This guide provides a selection of resources relevant to the subject area and is not intended to be a comprehensive list. All websites have been evaluated and details are correct at the time of publications.

Details correct at time of going to print. Please note that resources are continuously updated.

For further help or guidance, please contact a member of library staff.

This guide has been compiled by:

Jess Pawley
Senior Library Assistant
Musgrove Park Hospital Library Service

jessica.pawley@tst.nhs.uk

Issue 11
December 2016/January 2017
Contents
Click on a section title to navigate contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recent journal articles</td>
<td>3</td>
</tr>
<tr>
<td>Cochrane library</td>
<td>8</td>
</tr>
<tr>
<td>Guidelines</td>
<td>8</td>
</tr>
<tr>
<td>UpToDate</td>
<td>9</td>
</tr>
<tr>
<td>Reports, publications and resources</td>
<td>9</td>
</tr>
<tr>
<td>Topic Alerts and Updates</td>
<td>11</td>
</tr>
<tr>
<td>Training &amp; Networking Opportunities, Conferences, Events</td>
<td>12</td>
</tr>
<tr>
<td>Literature search service</td>
<td>12</td>
</tr>
<tr>
<td>Training and Athens</td>
<td>13</td>
</tr>
</tbody>
</table>

Library contact details:

Library
Musgrove Park Academy
Musgrove Park Hospital
Taunton
Somerset
TA1 5DA

Tel: 01823 34 (2433)

Email: library@tst.nhs.uk
Blog: http://librarymph.wordpress.com
@musgrovesompar
This is a list of journal articles on the topic of end of life. Some articles are available in the library or online via an OpenAthens password by following the full-text link. If you would like an article which is not available as full-text then please contact library staff.

Please note that abstracts are not always available for all articles.

---

**Title:** Patient reported outcome measures of quality of end-of-life care: A systematic review  
**Citation:** Maturitas, February 2017, vol./is. 96/(16-25), 0378-5122;1873-4111 (01 Feb 2017)  
**Author(s):** Kearns T.; Cornally N.; Molloy W.  
**Abstract:** End-of-life (EoL) care A term that encompasses all aspects of care related to death and dying provided towards the end of life [2]. There is no consensus in the literature regarding the time-frame it is applied to; definitions range from care in the last year of life, to care from time of terminal diagnosis until death. However, it is generally accepted as representing a broad continuum of care for people who are living with, or dying from terminal illness [1]. This wide focus lends itself to the description of care for patients with non-malignant chronic diseases where disease trajectories are more protracted, and prognostication less certain than for patients with cancer. is increasingly used as a generic term in preference to palliative care or terminal care, particularly with reference to individuals with chronic disease, who are resident in community and long-term care (LTC) settings. This review evaluates studies based on patient reported outcome measures (PROMS) of quality of EoL care across all health-care settings. From 1041 citations, 12 studies were extracted by searches conducted in EBSCO, Scopus, Web of Science, PubMed, Cochrane, Open Grey and Google Scholar databases. At present, the evidence base for EoL care is founded on cancer care. This review highlights the paucity of studies that evaluate quality of EoL care for patients with chronic disease outside the established cancer-acute care paradigm, particularly in LTC. This review highlights the absence of any PROMs for the estimated 60% of patients in LTC with cognitive impairment. Patient-reported outcomes (PROs) are critical to understanding how EoL care services and practices affect patients' health and EoL experience. PROMs describe the quality of care from the patient's perspective and add balance to existing clinical or proxy-derived knowledge on the quality of care and services provided.

---

**Title:** Advancing palliative and end-of-life science in cardiorespiratory populations: The contributions of nursing science.  
**Citation:** Heart & Lung, Jan-Feb 2017, vol/is. 46/1(3-6)  
**Author:** Grady, Patricia A11 National Institutes of Health, Bethesda, MD, USA. Electronic address: info@ninr.nih.gov.  
**Abstract:** Nursing science has a critical role to inform practice, promote health, and improve the lives of individuals across the lifespan who face the challenges of advanced cardiorespiratory disease. Since 1997, the National Institute of Nursing Research (NINR) has focused attention on the importance of palliative and end-of-life care for advanced heart failure and advanced pulmonary disease through the publication of multiple funding opportunity announcements and by supporting a cadre of nurse scientists that will continue to address new priorities and future directions for
advancing palliative and end-of-life science in cardiorespiratory populations. Published by Elsevier Inc.

Title: Common or multiple futures for end of life care around the world? Ideas from the 'waiting room of history'
Citation: Social Science and Medicine, January 2017, vol./is. 172/(72-79), 0277-9536;1873-5347 (01 Jan 2017)
Author(s): Zaman S.; Inbadas H.; Whitelaw A.; Clark D.

Abstract: Around the world there is growing interest in the manner in which care is delivered to people at the end of life. However, there is little unanimity on what constitutes a 'good death' and the appropriate societal responses to the issue of delivering culturally relevant and sustainable forms of end of life care in different settings are not subjects of broad agreement. In this critical conceptual paper we focus on the emerging narratives of global palliative care and offer an assessment of their implications. We relate this to calls to improve end of life care across jurisdictions and settings, attempts to map and grade the development of palliative care provision, and to the emergence of a widely recognised global 'quality of death index'. We consider an alternative approach to framing this debate, drawn from a subaltern and post-colonial studies perspective and suggest that adopting a truly global perspective will require acceptance of the plurality of past and present local problems and issues relating to end of life care, as well as the plural possibilities of how they might be overcome. In that context, we would not aim to universalise or privilege one particular global future for end of life care. Instead of homogenising end of life interventions, we seek to be open to multiple futures for the care of the dying.

Title: Predictors for Development of Pressure Ulcer in End-of-Life Care: A National Quality Register Study.
Citation: Journal of Palliative Medicine, January 2017, vol/is. 20/1(53-58)
Author: Carlsson, Maria E1; Gunningberg, Lena11 Department of Public Health and Caring Sciences, Uppsala University , Uppsala, Sweden .

Abstract: The scientific knowledge about pressure ulcers (PUs) is growing, but there is a shortage of studies of PUs at end of life. The recommendations regarding PU prevention in palliative care (PC) are based on consensus documents. To use data from a national register to identify predictors for development of PUs at the end of life. A retrospective, descriptive, and comparative study design was used. All deceased patients over 17 years old (n = 60,319) and registered in the Swedish Register of Palliative Care (SRPC) during 2014 were included. Logistic regression. In the full model, all health units except general palliative home care had a significantly high incidence of PUs than did the nursing homes. The well-known predictors of PUs in general, diabetes, postfracture state, infections, and multiple sicknesses, are predictors even in dying patients. Dementia was significantly associated with lower likelihood of PUs, while pain was associated with more PUs. Intravenous drip or enteral feeding was associated with a significantly decreased likelihood of developing PUs. The SRPC could be a unique resource for quality improvement and research. The present study cannot prove causation, but it can report correlations between background variables and PU prevalence. More studies, with different designs, are warranted to establish the roles of risk factors for PU in end-of-life care.
Title: Palliative Care Interventions for Patients with Heart Failure: A Systematic Review and Meta-Analysis.
Citation: Journal of Palliative Medicine, January 2017, vol/is. 20/1(84-92)
Author: Diop, Michelle S1; Rudolph, James L2; et al

Abstract: To systematically characterize interventions and effectiveness of palliative care for advanced heart failure (HF) patients. Patients with advanced heart failure experience a high burden of distressing symptoms and diminished quality of life. Palliative care expertise with symptom management and healthcare decision-making benefits HF patients. A systematic PubMed search was conducted from inception to June 2016 for studies of palliative care interventions for HF patients. Studies of humans with a HF diagnosis who underwent a palliative care intervention were included. Data were extracted on study design, participant characteristics, intervention components, and in three groups of outcomes: patient-centered outcomes, quality-of-death outcomes, and resource utilization. Study characteristics were examined to determine if meta-analysis was possible. The fifteen identified studies varied in design (prospective, n = 10; retrospective, n = 5). Studies enrolled older patients, but greater variability was found for race, sex, and marital status. A majority of studies measuring patient-centered outcomes demonstrated improvements including quality of life and satisfaction. Quality-of-death outcomes were mixed with a majority of studies reporting clarification of care preferences, but less improvement in death at home and hospice enrollment. A meta-analysis in three studies found that home-based palliative care consults in HF patients lower the risk of rehospitalization by 42% (RR = 0.58; 95% Confidence Interval 0.44, 0.77). Available evidence suggests that home and team-based palliative interventions for HF patients improve patient-centered outcomes, documentation of preferences, and utilization. Increased high quality studies will aid the determination of the most effective palliative care approaches for the HF population.

Title: A Protocol for the Control of Agitation in Palliative Care.
Citation: The American journal of hospice & palliative care; Dec 2016; vol. 33 (no. 10); p. 948-951
Author(s): Gonçalves, Ferraz; Almeida, Ana; Pereira, Sara

Abstract: Agitation is a distressing and dangerous behavior for all involved. To study a protocol effectiveness and safety. The time when the protocol was initiated and when the agitation was controlled, the number of doses needed and the complications observed were recorded. One hundred and thirty-five inpatients of a palliative care service were included. The most frequent diagnosis was head and neck cancer, 37 (27%). The protocol was used 584 times, from 1 to 31 times on each patient, median of 3 times. Five hundred and thirty-four (91%) agitation episodes were controlled with only the first dose of the protocol, without significant complications. From those results, it can be said that this protocol is effective and safe.

Title: Promoting patient-centred palliative care: a scoping review of the patient dignity question
Citation: Current Opinion in Supportive and Palliative Care; Dec 2016; vol. 10 (no. 4); p. 324-329
Author(s): Arantzamendi, Maria; Belar, Alazne; Martínez, Marina

Abstract: Purpose of review: In recent years, there has been a growing interest in promoting dignity in care, and specific interventions have been developed to include it at the end of life. The patient dignity question (PDQ) is a recent, novel and simple intervention that healthcare professionals can implement; however, little information is known about its impact. This scoping review aims to examine
and map out the PDQ literature. Recent findings: Studies suggest that patients, families and professionals have a positive view of the PDQ in that it helps to get to know patients and provide them with the best care possible. The PDQ seems to promote an environment of care focused on the person and the prevalence of more human aspects in clinical encounters between professionals and patients. This is especially so in situations in which human aspects of the healthcare relationship at baseline received lower marks. Healthcare professionals thought that performing the PDQ to determine what is important to the patient is a feasible and effective exercise. Summary: The published literature suggests that PDQ is a beneficial intervention for approaching and getting to know a patient as a person. More studies are needed that measure pre-post-PDQ changes and that demonstrate their impact on patient care. References

Title: Evidence for Implementation Strategies to Provide Palliative Care in the Neonatal Intensive Care Unit
Citation: Advances in Neonatal Care; Dec 2016; vol. 16 (no. 6); p. 430-438
Author(s): Quinn, Megan; Gephart, Sheila

Abstract: Background: Palliative care is a holistic framework that is designed to improve quality of life by identifying and treating distressing symptoms of life-threatening or complex conditions. Neonatal palliative care (NPC) has potential benefits for parents, staff, and patients, yet evidence suggests that implementation and utilization of organized NPC services are low. Purpose: The purpose of this study is to answer the clinical question: In neonatal intensive care, what evidence can be used to guide implementation of palliative care protocols? Search Strategy: A literature search was conducted using CINAHL (Cumulative Index of Nursing and Allied Health Literature), PubMed, and the Cochrane Library databases. Publications with a focus on neonates, neonatal intensive care unit, and implementation or evaluation of a palliative care protocol, team, or educational intervention were retained. Results: The search yielded 17 articles that fit with the following themes: NPC protocols or teams (n = 8), healthcare team needs (n = 3), and barriers to implementation (n = 6). Approaches to NPC implementation were varied, and outcome data were inconsistently reported. Healthcare team members cited a need for education and consistent, ethical delivery of NPC. Common barriers were identified as lack of NPC education, poor communication, and lack of adequate resources such as staff and space. Implications for Practice and Research: Successful team approaches included standardized order sets to initiate NPC, NPC education for staff, and references to NPC guidelines or protocols. Barriers such as lack of interdisciplinary cooperation, lack of appropriate physical space, and lack of education should be addressed during program development. Further research priorities for NPC include seeking parent perceptions, shifting focus from mostly end-of-life to an integrated model, and collecting outcome data with rigor and consistency.

Title: History taking and physical assessment in holistic palliative care.
Citation: British Journal of Nursing; Dec 2016; vol. 25 (no. 22); p. 1250-1255
Author(s): Donnely, Marie; Martin, Daphne

Abstract: In carrying out a holistic palliative care assessment the palliative care clinical nurse specialist needs to develop the knowledge and skill of history taking and health assessment to make safe and competent decisions with patients regarding the future management of their care. This article examines this process in making a differential diagnosis with particular reference to the
Title: Development and validation of the Palliative Care Knowledge Scale (PaCKS).
Citation: Palliative & supportive care; Dec 2016 ; p. 1-11
Author(s): Kozlov, Elissa; Carpenter, Brian D; Rodebaugh, Thomas L

Abstract:The purpose of this study was to develop a reliable and valid scale that broadly measures knowledge about palliative care among non-healthcare professionals. An initial item pool of 38 true/false questions was developed based on extensive qualitative and quantitative pilot research. The preliminary items were tested with a community sample of 614 adults aged 18-89 years as well as 30 palliative care professionals. The factor structure, reliability, stability, internal consistency, and validity of the 13-item Palliative Care Knowledge Scale (PaCKS) were assessed. The results of our study indicate that the PaCKS meets or exceeds the standards for psychometric scale development. Prior to this study, there were no psychometrically evaluated scales with which to assess knowledge of palliative care. Our study developed the PaCKS, which is valid for assessing knowledge about palliative services in the general population. With the successful development of this instrument, new research exploring how knowledge about palliative care influences access and utilization of the service is possible. Prior research in palliative care access and utilization has not assessed knowledge of palliative care, though many studies have suggested that knowledge deficits contribute to underutilization of these services. Creating a scale that measures knowledge about palliative care is a critical first step toward understanding and combating potential barriers to access and utilization of this life-improving service.
Reviews from December 2016

Palliative care interventions in advanced dementia

*NEW*

Cochrane Clinical Answers

Cochrane Clinical Answers covers 32 Clinical Specialties and provide a readable, digestible, clinically focused entry point to rigorous research from Cochrane systematic reviews. They are designed to be actionable and to inform decision making at the point of care. Each Cochrane Clinical Answer contains a clinical question, a short answer, and an opportunity to ‘drill down’ to the evidence from the Cochrane Review. The evidence is displayed in a user friendly format, mixing narrative, numbers and graphics. The target audience for Cochrane Clinical Answers is healthcare practitioners and professionals, and other informed health care decision-makers. Cochrane Clinical Answers have been developed by Cochrane Innovations Ltd. and Wiley Online Library.

November 2016

In terminally-ill people, how does home-based end-of-life care compare with usual care at improving outcomes?

GUIDELINES

NICE Guidelines

Current Guidelines

NG61- End of life care for infants, children and young people with life-limiting conditions: planning and management- December 2016

NG31- Care of dying adults in the last days of life- December 2015

Updated Guideline

CG140- Palliative care for adults: strong opioids for pain relief- updated August 2016
What's new from our clinical decision-making tool on the topic of end of life care.

**UpToDate (Access for Musgrove Park Staff only)**

Please contact library staff for details on how to access these resources; you will need an Athens password.

### REPORTS, PUBLICATIONS AND RESOURCES

**SCIE (Social Care Institute for Excellence) End of Life Care**

**National Council for Palliative Care**

**European Association for Palliative Care**

**European Association for Palliative Care**

*14th World Congress of the European Association for Palliative Care* - information from the 14th World Congress of the European Association for Palliative Care, held in May 2015

**BMA**

*End-of-life care and physician-assisted dying*

**Royal College of Physicians**

*Palliative and end of life care toolkit*

**National Institute for Health Research**

*Themed review- Better Endings: Right care, right place, right time*

**NHS England**

*Transforming end of life care in hospitals: the route to success ‘how to’ guide*
e-Learning for Healthcare

End of life care: e-learning modules to support NICE Guideline NG31 Care of Dying Adults in the Last Days of Life

Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020
New ambitions raise the bar for end of life care. National framework for action urges local leadership to be at forefront of improvement in end of life care.

The National Palliative and End of Life Care Partnership, made up of statutory bodies including NHS England, the Association of Adult Social Services, charities and groups representing patients and professionals has developed a framework for action in making palliative and end of life care a priority at local level.

Each community is prepared to help- Guidance on Ambition 6 of the national framework
New guidance has been published which includes practical advice aimed at strengthening the capacity of communities to care for dying people and their families. The guidance – entitled Each Community is Prepared to Help - has been produced by the National Council for Palliative Care (NCPC), Public Health Palliative Care UK and Hospice UK. It contains a range of practical ideas for working with hospices, hospitals, Health & Wellbeing Boards, Clinical Commissioning Groups and other relevant organisations in rolling out community development in end of life care.

NEW National Council for Palliative Care report
The National Council for Palliative Care (NCPC) have published a new report Staff prepared to care? Capacity and competence in the end of life care workforce.

CQC Review A different ending: End of life care review
This review of end of life care found that people from certain groups in society sometimes experience poorer quality care because providers do not always understand or fully consider their needs. In light of this, the report argues that some commissioners and providers might not be fulfilling their duties under the Equality Act 2010 as all public bodies have a legal duty to consider the needs of a range of equality groups when carrying out their day-to-day work. The review identified examples of good practice, but found that action is needed to make sure everyone has the same access to high quality, personalised care at the end of their lives, regardless of their diagnosis, age, ethnic background, sexual orientation, gender identity, disability or social circumstances.

Dying with Dementia- National Dementia Intelligence Network and National End of Life Care Intelligence Network briefing
This briefing is written in the context of Dementia and the End of Life Care Strategy, where everyone, including people with dementia, approaching end of life should experience high quality, compassionate and joined-up care.

Public Health England- Community based end of life care commissioning
This report is aimed at commissioners of end of life care services to support new ways of commissioning through using public health approaches to build compassionate communities. The key objectives of the research were to understand the awareness and knowledge of community end of life care across a number of key audiences; their perceptions of community end of life care; their experiences of end of life care and any community initiatives; and any improvements that could be made to community end of life care.
Dying to care: A report into social care at the end of life
In this report, Marie Curie, the Association of Palliative Care Social Workers, Hospice UK and MND Scotland call for a new approach to make sure that people living with a terminal illness and their carers in Scotland get the social care support they need to allow them to make the most of the time they have left.

Care after death: Registered nurse verification of expected adult death (RNVoEAD) guidance
The aim of this guideline and the accompanying competency assessment tool is to provide a framework for the timely verification of expected adult deaths by experienced (assessed as competent) registered nurses. It will enable staff to care appropriately for the deceased, in line with local policy, and minimise distress for families and carers following an expected death at any time of the day/night/week. It is in line with the person and family centred care recommended in national documents.

ABSTRACTS AVAILABLE VIA LINKS BELOW- FOR FULL-TEXT PLEASE ASK LIBRARY STAFF

An integrative review of how families are prepared for, and supported during withdrawal of life-sustaining treatment in intensive care.
FREE FULL TEXT

Commissioning care for people with dementia at the end of life
BMJ Open, 2016, December Vol 6 (12)

Challenges to access and provision of palliative care for people who are homeless: a systematic review of qualitative research
BMC Palliative Care December 2016; 15: 96
FREE FULL TEXT

Establishing a nurse practitioner model to enhance continuity between palliative care settings
International Journal of Palliative Nursing 2016; 22 (12): 581-585
Ongoing training: events throughout the year-
http://www.endoflifecareintelligence.org.uk/events/

15th World Congress of the European Association for Palliative Care - 11th-13th May 2017, Madrid

5th International Public Health and Palliative Care Conference - 18th-20th September 2017, Ottawa, Ontario, Canada- Includes links to past conferences and presentations

LITERATURE SEARCH SERVICE

Looking for the latest evidence-based research but haven’t got time to trawl the databases?
Do you need a literature search carried out?
Do you need to find evidence to support an improvement?
Do you want to know how something has been done elsewhere and whether it worked?

Library staff provide a literature search service for busy clinicians who are pressed for time.

To request a search please complete and return the appropriate form, providing as much information as possible. Alternatively if you would like an assisted search training session, where we will sit down with you and go through the steps of a literature search, then please contact the library.

Please click here to access a literature search request form. Simply complete and email back to us.
Most electronic resources are available via an Athens password. You can register for this via the Library intranet page, or from home [here](#).

Please note that registering from home will take longer as it will need to be verified that you are NHS staff/student on placement.

The library offers training on how to access and use Athens resources, as well as an introductory course on critical appraisal. You can book a course through the Learning and Development intranet page, or by contacting the library directly.