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**Literature search results**

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**Search details**

End of Life care for patients with Learning Disability

**Resources searched**

NHS Evidence; TRIP Database; Cochrane Library; BNI; CINAHL; EMBASE; HMIC; MEDLINE; PsychINFO; Google Scholar

*Database search terms*: learning disability (ies), intellectual disability (ies), end of life, end of life care, death, palliative care, nurses/nursing

*Google search string*: end of life care and learning disability

**Summary**


**Guidelines**


Caring For People with a Learning Disability in General Hospital Settings 2010. GAIN.


Pages 299 – 303.
Evidence-based reviews


Published research

1. End-of-life care and people with intellectual disabilities: A multi-media educational resource
   Author(s) McLaughlin D., Barr O., McIlfatrick S., McConkey R.
   Citation: Journal of Intellectual Disability Research, July 2012, vol./is. 56/7-8(766), 0964-2633 (July 2012)
   Publication Date: July 2012
   Abstract: Aim: This study aimed to develop and evaluate a multi-media educational resource in palliative and end-of-life care for specialist palliative care and intellectual disability (ID) services which promoted collaborative working. Method: A mixed-methods design involving three phases was used. Qualitative data were obtained from semi-structured interviews with a purposive sample of professionals (n = 30) and family carers (n = 5) and from two focus groups with people with ID (n = 17). Data were content analysed as outlined by Newell and Burnard (2006). This identified training needs and issues in end-of-life care for this population which were confirmed through quantitative data from services in a regional scoping study analysed using descriptive statistics. A DVD and manual were developed and evaluated with twelve professionals. Data were collected using a solicited diary, the Readiness for Inter-professional Learning Scale, Likert scales and an evaluation questionnaire. Thematic analysis and descriptive statistics appropriate to data were used. Results: Findings suggest that this resource demonstrates the need for and benefits of partnership working and transferability of this learning to practice could address issues at end-of-life for people with ID. Conclusions: Findings of this study have importance for partnership working and service provision in end-of-life care for this population.
   Source: EMBASE
   Available in print at Grantham Hospital Staff Library
   Available in print at ULHT journal article requests. Complete the online form to obtain articles.

2. Communicating with children and young people: A Toolkit to support end of life care
   Author(s) Read S.
   Citation: Journal of Intellectual Disability Research, July 2012, vol./is. 56/7-8(668), 0964-2633 (July 2012)
   Publication Date: July 2012
   Abstract: Aim: A toolkit can be described as a set of tools designed for a specific type of work, kept in a special box or bag; or a collection of information, resources or advice for a specific area or activity. This paper introduces a toolkit, funded by the UK Department of Health, entitled Communicating with Children, Young People and Families Where There is a Learning Disability, to help professional carers when providing end-of-life care. This presentation provides the rationale for the project, describes how the toolkit was developed, introduces the toolkit itself, and explores its potential from an educational and practical perspective. Method: Action research provided a framework for development of the toolkit and involved a range of practitioners. Results: Collaborative approaches to the toolkit development enabled the resource to be flexible and practical. The toolkit has 26 components to help palliative care professionals in a variety of healthcare settings and contexts. Conclusions: Toolkits need to be accessible, portable, flexible and cost effective to reach their maximum potential. They also have to fit the purpose of use. Action research provided an appropriate framework to enable a range of practitioners to work together to ensure the resource was a fit with purpose.
   Source: EMBASE
   Available in print at Grantham Hospital Staff Library
3. Developing a network for improving palliative care for people with ID
Author(s) Tuffrey-Wijne I., McKie A.
Citation: Journal of Intellectual Disability Research, July 2012, vol./is. 56/7-8(670), 0964-2633 (July 2012)
Publication Date: July 2012
Abstract: Aim: To improve end of life support for people with intellectual disabilities (ID), and to support practitioners and carers who work in this area. Method: The Palliative Care for People with Learning Disabilities (PCPLD) Network was founded in the UK in 1998. It has developed significantly in recent years, most significantly through developing a website (www.pcpld.org). The Network's aims are to raise awareness of the palliative care needs of people with ID, promote best practice in the palliative care of people with learning ID, and enhance collaboration. The PCPLD Network does this by: providing a forum which facilitates communication between members of the Network through the website and through regional meetings, supporting and promoting educational opportunities, and recognizing best practice through an annual award scheme. Results: The Network's membership has tripled in the past year, and includes non-UK members. Members are mostly professionals working with people with ID at the end of life. Successful conferences and the award for best practice have contributed to achieving its aims. Conclusions: There is a clear need for networking and sharing best practice among professionals. New opportunities for e-networking need to be explored further.
Source: EMBASE
Available in print at Grantham Hospital Staff Library
Available in print at ULHT journal article requests. Complete the online form to obtain articles.

4. Meeting the health needs of older people with learning disabilities.
Author(s) Jenkins R
Citation: British Journal of Nursing, vol./is. 21/8(468-73), 0966-0461;0966-0461 (2012 Apr 26-May 9)
Abstract: The increasing population of older people with learning disabilities may lead to higher demand for contact with registered nurses. To date, little research has been undertaken regarding the role of registered nurses in meeting the health and care needs of this client group. In this article, the author reports on the second stage of a three-stage research study that used six case studies to explore this issue. Implications for nursing were identified in areas such as health needs, record keeping, medication, advocacy, social aspects, ageing in place, percutaneous endoscopic gastrostomy (PEG) feeding, spirituality and end-of-life care. The author concludes that registered nurses will need to continue to remain up to date to meet the complex needs of older individuals with learning disabilities.
Source: Medline
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Available in print at Lincoln County Hospital Professional Library

5. Practical approaches toward improving end-of-life care for people with intellectual disabilities: effectiveness and sustainability.
Author(s) Cross H, Cameron M, Marsh S, Tuffrey-Wijne I
Citation: Journal of Palliative Medicine, March 2012, vol./is. 15/3(322-6), 1557-7740;1557-7740 (2012 Mar)
Publication Date: March 2012
Abstract: BACKGROUND: People with intellectual disabilities (ID) experience many barriers in accessing quality health care for serious and terminal illness, including delayed diagnosis, as signs and symptoms of illness are misinterpreted. There is growing evidence that palliative care services are underused by people with ID. METHODS: A 3-year project aimed at exploring ways of increasing access to palliative care services by people with ID...
in South West London was conducted. A project group designed training sessions for both ID and palliative care staff involving four hospices and 228 care homes. Evaluators used interactive cycles involving discussions and interviews to map learning and identify constructive ways forward.

RESULTS AND CONCLUSION: In general, the study found that there was a lack of understanding of each other's role between palliative care professionals and ID staff, with each unsure of what the other service is providing and how it is run. Recommendations include securing a development worker for ID and end-of-life care; conducting training for ID care staff; establishing how ID services are organized within the local area; linking to national training programs; ensuring that senior management is proactively involved; and ensuring that the goals of any initiative are clear and measurable.

Source: Medline
Available in print at ULHT journal article requests. Complete the online form to obtain articles.

Author(s) Barber, Chris
Citation: British Journal of Healthcare Assistants, Feb 2012, vol. 6, no. 2, p. 74-77, 1753-1586 (February 2012)
Publication Date: February 2012
Abstract: 2nd of 2 articles on death, dying and bereavement in relation to people with a learning disability, focusing on issues surrounding end-of-life care. Legal and ethical issues are discussed, including accountability, do not resuscitate orders, withdrawal of medical treatment and support, making wills and the use of drugs which can hasten the end of life. Spirituality is considered, and the role of health care assistants in supporting patients at the end of life is described, as well as supporting parents experiencing bereavement because of expecting a child with a learning disability. [ORIGINAL] 16 references
Source: BNI
Available in print at Grantham Hospital Staff Library
Available in print at ULHT journal article requests. Complete the online form to obtain articles.
Available in print at Pilgrim Hospital Staff Library
Available in print at Lincoln County Hospital Professional Library

7. End of life care guide will help people to 'a good death'.
Author(s) Davis, C
Citation: Learning Disability Practice, May 2011, vol. 14, no. 4, p. 6-7, 1465-8712 (May 2011)
Publication Date: May 2011
Abstract: Comments on The Route to Success in End of Life Care: Achieving Quality for People with Learning Disabilities, the National End of Life Care Programme's palliative care guide for learning disability nurses and other professionals. The palliative care resources included in the guide and professionals' responses to them are described. [(BNI unique abstract)] 2 references
Source: BNI
Available in fulltext at EBSCOhost
Available in print at ULHT journal article requests. Complete the online form to obtain articles.

Author(s) Ryan, K, Guerin, S, Dodd, P
Publication Date: May 2011
Abstract: Qualitative research examining the perceptions of learning disability service staff regarding their role during the terminal care of a client. Staff, including nurses and other health and social care professionals, were analysed to explore the emotional impact of caring for a client at the end of life, experiences of being excluded by relatives or other professionals and coping strategies. [(BNI unique abstract)] 31 references
Source: BNI
Available in print at ULHT journal article requests. Complete the online form to obtain articles.
Available in print at Lincoln County Hospital Professional Library
**Author(s)** Holmstrom, R
**Citation:** Learning Disability Practice, Mar 2011, vol. 14, no. 2, p. 18-19, 1465-8712 (March 2011)
**Publication Date:** March 2011
**Abstract:** The role of learning disability nurses in children's hospices. The experiences of learning disability nurses at 2 children's hospices are described and the specific challenges of caring for life-limited children with learning disabilities are described, including communication difficulties, interpreting a child's needs and working with families to prepare them for the child's death. [(BNI unique abstract)] 0 references
**Source:** BNI
Available in fulltext at EBSCOhost
Available in print at ULHT journal article requests. Complete the online form to obtain articles.

10. Award-winning nurse who gives patients the best possible journey.
**Author(s)** Trueland, J
**Citation:** Learning Disability Practice, Nov 2010, vol. 13, no. 9, p. 6-7, 1465-8712 (November 2010)
**Publication Date:** November 2010
**Abstract:** The role of Dorothy Matthews, the UK's only Macmillan nurse who specialises in providing terminal care for people with learning disabilities. Her career, motivation to specialise in terminal care and day-to-day work are outlined. Particular challenges of breaking bad news and obtaining consent in end-of-life care planning are discussed, and her end-of-life care guide for learning disability carers is highlighted. [(BNI unique abstract)] 0 references
**Source:** BNI
Available in fulltext at EBSCOhost
Available in print at ULHT journal article requests. Complete the online form to obtain articles.

11. Learning disabilities and dying.
**Author(s)** Crawford, Hannah
**Citation:** Journal of Palliative Medicine, April 2010, vol./is. 13/4(361-363), 1096-6218;1557-7740 (Apr 2010)
**Publication Date:** April 2010
**Abstract:** The focus on good quality palliative care for our service users is still a challenge. I recently worked with a gentleman with learning disabilities who was dying. Despite the fact that there were several services working with him, I am still not sure we achieved a "good death" for him, and this experience led me to reflect on some of the challenges in this area. (PsycINFO Database Record (c) 2012 APA, all rights reserved)
**Source:** PsycINFO
Available in fulltext at EBSCOhost
Available in print at ULHT journal article requests. Complete the online form to obtain articles.

**Author(s)** Matthews D, Gibson L, Regnard C
**Citation:** British Journal of Hospital Medicine, January 2010, vol./is. 71/1(40-3), 1750-8460;1750-8460 (2010 Jan)
**Publication Date:** January 2010
**Abstract:** The End of Life Care Strategy takes as inclusive an approach as possible, but can it make a difference for people with learning disabilities who are dying? Therefore we must ask ourselves 'Does one size fit all?'
**Source:** Medline
Available in fulltext at EBSCOhost
Available in print at ULHT journal article requests. Complete the online form to obtain articles.
13. Improving care for patients with intellectual disabilities.
**Author(s)**: Duplock, L., Oliver, D., Forrester-Jones, R.
**Citation**: European Journal of Palliative Care, Mar 2009, vol. 16, no. 2, p. 66-68, 1352-2779 (Mar-Apr 2009)
**Publication Date**: March 2009
**Abstract**: Report of 2 research studies on knowledge and attitudes of learning disability and palliative care staff regarding people with learning disabilities needing palliative care. Focus groups of professionals from both fields identified gaps in knowledge and difficulties of caring for terminally ill learning disabled people and discussed inclusion of patients in decision making, place of death and preparation for death. [(BNI unique abstract)] 18 references
**Source**: BNI
Available in print at ULHT journal article requests. Complete the online form to obtain articles.

**Author(s)**: Li S, Ng J.
**Citation**: Palliative Medicine, 01 December 2008, vol./is. 22/8(949-955), 02692163
**Publication Date**: 01 December 2008
**Abstract**: This qualitative study identifies areas of expertise and deficits in the specific knowledge and practical skills of nurses in the care of dying patients with profound learning disabilities in one NHS Primary Care Trust in the UK. In response to these findings, we have developed a simple observational checklist applicable to profound learning disability nursing to identify disease-related personality and physiological changes. The method consists of a descriptive case study of five nurses qualified in learning disabilities nursing, using semi-structured interviews. The disease trajectory was used as a framework of reference to guide the data analysis. Themes showed were 'certainty of knowing' about disease-related changes in patients' habits and behaviour and 'uncertainty and ambiguity' in the patho-physiology of advanced diseases and disease progression. This study interprets a lack of patho-physiological knowledge in both malignant and non-malignant diseases leading to delayed diagnosis and timely intervention. Timeliness of observation and intervention are emphasised.
**Source**: CINAHL
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Available in print at Lincoln County Hospital Professional Library

15. 'Too young to die!' A cognitive behavioural approach to dealing with 'death anxiety'.
**Author(s)**: Mirow, R.
**Citation**: Learning Disability Practice, Sep 2008, vol. 11, no. 7, p. 18-21, 1465-8712 (September 2008)
**Publication Date**: September 2008
**Abstract**: Case study outlining the use of cognitive behaviour therapy in helping a 75 year old man with moderate learning disability deal with obsessive and irrational thoughts about dying. Assessment and case formulation, rationale for cognitive behaviour therapy and treatment evaluation are discussed. [(BNI unique abstract)] 18 references
**Source**: BNI
Available in fulltext at EBSCOhost
Available in print at ULHT journal article requests. Complete the online form to obtain articles.
Available in print at Lincoln County Hospital Professional Library
Communication difficulties and intellectual disability in end-of-life care
I Tuffrey-Wijne, L Mcenhill - ... journal of palliative ..., 2008 - ddhospicepalliativecare.org
... distress in people with severe communication difficulties: developing and assessing the Disability Distress Assessment ... Project': an ethnographic study of the experiences of people with learning disabilities who ... i5(l): 7-11 Tuffrey-Wijne I, Hogg J, Curfs L (2007a) End-of-life ...