

Northumbria Research Link

Citation: Merlane, Helen and Cauwood, Laura (2020) Core principles of end-of-life care. British Journal of Nursing, 29 (5). pp. 280-282. ISSN 0966-0461

Published by: Mark Allen Publishing

URL: <https://doi.org/10.12968/bjon.2020.29.5.280> <<https://doi.org/10.12968/bjon.2020.29.5.280>>

This version was downloaded from Northumbria Research Link:
<http://nrl.northumbria.ac.uk/id/eprint/42521/>

Northumbria University has developed Northumbria Research Link (NRL) to enable users to access the University's research output. Copyright © and moral rights for items on NRL are retained by the individual author(s) and/or other copyright owners. Single copies of full items can be reproduced, displayed or performed, and given to third parties in any format or medium for personal research or study, educational, or not-for-profit purposes without prior permission or charge, provided the authors, title and full bibliographic details are given, as well as a hyperlink and/or URL to the original metadata page. The content must not be changed in any way. Full items must not be sold commercially in any format or medium without formal permission of the copyright holder. The full policy is available online: <http://nrl.northumbria.ac.uk/policies.html>

This document may differ from the final, published version of the research and has been made available online in accordance with publisher policies. To read and/or cite from the published version of the research, please visit the publisher's website (a subscription may be required.)



**Northumbria
University**
NEWCASTLE



UniversityLibrary

An Introduction to End of Life Care

Abstract

This article will provide an overview of the need for End of Life Care provision, differentiate between End of Life Care, Palliative Care and Terminal Care, highlight the difficulties in recognising when a patient may be approaching end of life and provide an overview of the Gold Standards Framework (GSF) (2016). The Five Priorities of Care (Leadership Alliance for the Care of Dying People, (LACDP) 2014) will be used as a framework for delivering high standards of end of life care.

Introduction

The Office of National Statistics (ONS), (2018) reported 533,253 registered deaths in England and Wales in 2017; increasing 1.6% from 2016, and the highest recorded since 2003. The number of deaths and age-specific mortality rates for people 90 years and over also increased. With an aging population, and an increasing incidence of long-term conditions (some cancers fitting into this category as well as dementia) there will be a growing emphasis on end of life care provision (National Palliative & End of Life care partnership, 2015).

In order to provide high quality end of life care, understanding what is meant by the term is crucial. Within the literature, and amongst professionals, the terms end of life, palliative care and terminal care are often used interchangeably; however, each term has distinct differences, and prognostic implications (Hui et al, 2014). It is imperative that nurses and health care professionals understand the defining characteristics of each term, so that they can recognise the phase appropriate for the patient and be able to respond to their care needs in a timely manner.

Palliative Care

Palliative care is an approach which encompasses comfort focused, holistic care to any patient with a life limiting illness, including patients who are receiving curative treatment. The focus is on enhancing quality of life, by promoting comfort, respect, dignity and supporting the dying person and those close

to them. The approach can be used at any point within the patients' disease trajectory. The World Health Organisation (2018) recognises that palliative care is applicable to patients early within their illness, and used alongside life-prolonging treatments, such as chemotherapy and radiotherapy, with some people receiving palliative care for years. However, it does include caring for those nearing the end of their lives. This is known as end of life care.

End of Life Care

The End of Life Care Strategy (Department of Health, (DH) 2008) suggests that End of life care planning should commence for patients who are expected to die within 12 months. However, goes on to state that identifying the beginning of end of life care is variable, and depends on the person (who may recognise that they are approaching end of life), professional perspective, the disease, and the stage that the patient is at within the disease trajectory. The principles of Palliative Care are embedded in end of life care, with the focus being on enabling patients with an advanced, progressive, incurable illness to live as well as possible until they die; this includes supporting the needs of the patient, family, and having a management plan to support their holistic needs (LACDP, 2014).

Terminal care

There is a great deal of ambiguity around the meaning of the term dying, with it sometimes being used in the same context as palliative and end of life care. Nyatanga (2017) suggests that people are thought to be dying when their view of living is threatened by a life limiting illness, whereas Hui et al, (2014) defines dying as the hours or days preceding imminent death.

Fig 1

General Indicators of decline and increasing needs

- General physical decline, increasing dependence and need for support.
- Repeated unplanned hospital admissions.
- Advanced disease – unstable, deteriorating, complex symptom burden.
- Presence of significant multi-morbidities.
- Decreasing activity – functional performance status declining (e.g. Barthel score) limited self-care, in bed or chair 50% of day and increasing dependence in most activities of daily living.
- Decreasing response to treatments, decreasing reversibility.
- Patient choice for no further active treatment and focus on quality of life.
- Progressive weight loss (>10%) in past six months.
- Sentinel Event e.g. serious fall, bereavement, transfer to nursing home.
- Serum albumin <25g/l
- Considered eligibility for DS1500 payment

(GSF, 2016)

Five Priorities of Care

Defining the point at which a patient may be nearing the end of their lives or dying is dependent on several factors (Fig.1), and regardless, there should be a continuum of care including an ongoing assessment of patient and family needs and responding in an appropriate and timely manner (LACDP, 2014). Following a review of the Liverpool Care Pathway (LCP), which highlighted inconsistencies in the provision of good end of life care, one of the key recommendations was that it should be phased out (DH, 2013). In response, the LACDP (2014) published a response in the One Chance to Get it Right document, highlighting Five Priorities of care (Fig 2) based on the wishes of the dying patient and family, rather than the processes. A key consideration is that these priorities can be applied regardless of the environment, with the focus being on the provision of high quality, patient centred care.

Fig 2

Insert a diagram of the 5 priorities of care here

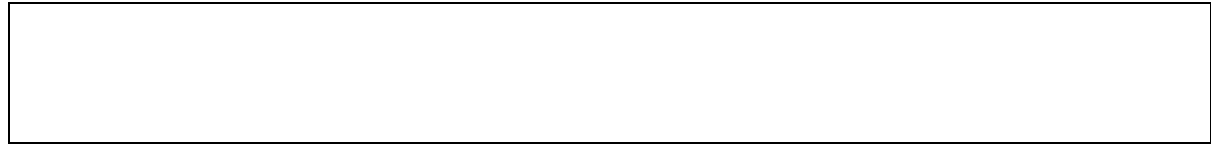
The magazine can find a diagram that is not copy right to insert here.

Priority 1: Recognising

The LACDP (2014) suggests that the point at which treatment ends, and care becomes palliative, should be a continuum, where the patients' needs are constantly assessed by a senior clinician and responded to in a timely and sensitive manner. Sharing the uncertainty, and voicing concerns that the patient may be dying with the patient (if conscious) and family is the most honest approach and a deterioration in the patients' condition and should be the trigger for expressing their concerns (Regan, Tapley and Jolley, 2014).

However, it has already been established that recognising the possibility that a patient may be approaching end of life, or indeed dying is difficult. The GSF (2016), is a framework used within the community, care homes and acute setting, which enables early recognition of patients with life limiting conditions, and as a result the patients' needs can be better anticipated and addressed and important conversations regarding future planning and patient's wishes, can happen in a timely manner. The GSF (2016) provides a three-step approach (Fig 3), which provides health care professionals with general and specific considerations which will aid them in making a decision that a patient may be deteriorating. However, as Kennedy et al (2014) state, the complexity of identifying clinical indicators of dying across different diseases is challenging, and therefore should be based on patient needs rather than the diagnosis.

Fig 3. Is there anyway the proactive Identification Guidance (PIG) flowchart can be incorporated? I have provided the link.
<https://www.goldstandardsframework.org.uk/cd-content/uploads/files/PIG/NEW%20PIG%20-%20%20%2020.1.17%20KT%20vs17.pdf>



Priority 2: Communication

Open and honest communication with the dying patient and those important to them is paramount. The LACDP (2014) state that all discussions should be in plain language, appropriate and avoid euphemisms. All documentation should be accessible to all members of the health care team who are involved in the patient's care. Communication should be regular, proactive, and respect the privacy and confidentiality of the person who is dying and those important to them. Staff must also check the patient and others' understanding, clearly documenting any conversations occurring in relation to treatment goals, plan of care, prognosis and any concerns raised by the patient or those important to them. These conversations should be ongoing taking into consideration changes in the patient's condition and whether or not the patient has capacity (Robinson et al, 2013, Mental Capacity Act, 2005).

Priority 3: Involve

In the first instance, it is important to ascertain the extent to which patients want to be involved in decisions about their care, as patients and those important to them differ in their wish to be involved in decisions around care and treatment. Health care staff need to sensitively enquire how much each person wants to be involved at each stage and, in order to accomplish this, the dying patient and their families, must be given the names of the senior doctor responsible for their care and then the name of the nurse responsible for leading care (LACDP, 2014). Consideration should also be given to patients who have lost capacity. For those who have lost capacity, any decision made must be in their best interests and involve the patient as much as possible (Mental Capacity Act, 2005), .

Priority 4: Support

Families and those important to the dying person have their own needs, which can be overlooked by themselves and others during this difficult period (Broom and Kirby, 2012). Therefore, healthcare

professionals must regularly assess and address the needs of families and those important to the dying person, as the family's experience of a loved one's final illness and death impacts on their own responses to future healthcare (Sykes, 2015). Healthcare professionals must ensure that even those who appear to be coping are supported and their needs actively explored. It is worthwhile considering that carers may wish to participate in caring for the dying person and must be supported by staff to do so (LACDP, 2014).

Priority 5: Plan and Do

An individual plan of care should be developed in collaboration with the patient and those important to the patient, in order to meet the patients' care needs and treatment preferences (LADCP, 2014). This plan should be regularly reviewed as the patient's wishes and condition may change. Two crucial findings from the Neuberger report (2013) were the discovery that hydration and nutrition were being inappropriately withheld from dying patients, and symptom control was not individualised. Therefore, it is important that patients are offered

- Food and drink for as long as it is safe to do so,
- Timely symptom control measures
- Ongoing holistic assessment (psychological, spiritual, cultural and religious needs)
- Open and honest, clearly documented communication
- Referral to other members of the multi professional team, including seeking advice from the Specialist Palliative Care Team if necessary (LADCP, 2014).

Conclusion

Recognising the point at which a patient with a life limiting illness may be approaching end of life care or indeed dying is difficult. Therefore, it is imperative that nurses identify and respond in a timely manner to a change in the patient's condition, and utilise the Proactive Identification Guidance which will enable them to recognise that a patient may be approaching end of life. Application of the Five

Priorities of Care framework ensures that the patient receives individual, patient-centered holistic care, and the needs of those important to the patient are also considered, for as Dame Cicely Saunders (1918 - 2005) famously quoted, “How people die remains in the memory of those who live on”.

References

Broom, A. and Kirby, E. (2013) The end of life and the family: hospice patients' views on dying as relational. *Social Health Illness*. 35 (4), pp. 499-513

Department of Health. (2008) *End of Life Care Strategy; Promoting high quality care for all adults at the end of life*. Available at:

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/136431/End_of_life_strategy.pdf (Accessed July 20119)

Department of Health (2013) *More Care less Pathway: A Review of the Liverpool Care Pathway*. Available at

[:https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf) (Accessed July, 2019)

Gold Standards Framework (2016) *The Gold Standards Framework Proactive Identification*

Guidance Available at:

<https://www.goldstandardsframework.org.uk/cd-content/uploads/files/PIG/NEW%20PIG%20-%20%20%2020.1.17%20KT%20vs17.pdf> (Accessed November, 2019)

Hui D., Nooruddin, M., Didwaniya, Z., Dev R., De La Cruz, M., Kim,S., Kwon, J., Hutchins,R.,Liem, C and Bruera, E. (2014) Concepts and Definitions for “Actively Dying”, “ End of Life care”, “Terminally Ill,” “ Terminal Care” and “Transition Care”: A Systematic Review. *Journal of Pain & Symptom Management*. 47 (1) pp 77 -89

Kennedy,C., Brooks-Young,P., Gray,C., Larkin,P., Connolly,M., Wilde-Larsson,B., Larsson,M., Smith,T and Chater,S. (2014) Diagnosing Dying: an integrative literature review. *BMJ Supportive & Palliative Care* 4: pp 263 - 270

Leadership Alliance for the Care of Dying People (2014) *One Chance to get it Right*. Available at: [http://wales.pallcare.info/files/One chance to get it right.pdf](http://wales.pallcare.info/files/One_chance_to_get_it_right.pdf) (Accessed June 2019)

Mental Capacity Act (2005) Available at: <https://www.legislation.gov.uk/ukpga/2005/9/contents>
(Accessed June 2019)

National Palliative and End of Life Care Partnership (2015) *Ambitions for palliative and end of life care: a national framework for local action 2015-2020*. Available at: <http://www.endoflifecareambitions.org.uk> (Accessed June 2019).

Nyatanga, B (2017) The idea of living, dying, life and death. In *Palliative and End of Life Care Nursing* 2nd edition (Nicol, J and Nyatanga, B, 2017) p5-230 London: Sage

Office of National Statistics (2018) *Deaths broken down by age, sex, area and cause of death sourced from the deaths register*. Available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths> (Accessed July 2019)

Regan, A., Tapley, M and Jolley, D (2014) Improving end of life care for people with dementia. *Nursing Standard* 28, (48) pp 37 - 43

Robinson, L., Dickinson, C., Bamford, C., Clark, A., Hughes, J and Exley, C. (2013) A qualitative study: professional's experiences of advance care planning in dementia and palliative care, 'a good idea in theory but....' *Palliative Medicine*. 27 (5), pp 401 – 408

Sykes, N. (2015) One Chance to get it Right: understanding the new guidance for care of the dying person. *British Medical Bulletin*. 115 (1), pp. 143-150

World Health Organisation (WHO) (2018) *Definition of Palliative Care*. Available at: <http://www.who.int/cancer/palliative/definition/en> (Accessed July, 2019).