

Research Study

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Evolving A Sustainable Model of Guidance to Support Individual Care of Dying Patients: A National Perspective

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ABSTRACT

Background: Guidance supporting care delivery in the last days of life has been implemented across Wales for the past 16 years. Continuous central monitoring and recent developments for care of the dying patient in England, provided the impetus to undertake a thorough overhaul of the Welsh guidance.

Methods: Recommendations of the National Health Service (NHS) Leadership Alliance for care of dying people, supported by outcomes of a Welsh electronic survey, resulted in prototype guidance being drawn up. The new guidance was tested in a variety of care settings and agreement reached it was fit for purpose.

Outcomes: This paper reports on the progress of reviewing the previous process-led guidance to address the current focus on providing individualised care for the patient and those important to them at the end-of-life. The new guidance resulting from this process is discussed, quality monitoring systems are described and the national progress with implementation across Wales reported.

KEY WORDS: Dying patients; Supporting care; Continual quality monitoring; Benchmarking; Last days of life.

BACKGROUND

The way we die is important not only for the person dying but more explicitly for those who live on. The Economist Intelligence Unit (EIU)¹ report ranked end-of-life care in the United Kingdom as best in the world, although room for improvement continued to be identified.

For the healthcare professional providing care the challenges can be multiple and care interventions complex. In 2015, the National Institute for Clinical Excellence (NICE) issued new guidelines to support the delivery of end-of-life care in all care settings.² In Wales, the NHS is devolved to the Welsh Government and managed locally through regional health boards. Each health board is responsible for all primary and secondary care provision in its area.

Based on the National Council for Palliative Care guidelines “Changing Gear”³ the ‘Welsh Integrated Care Priorities’ (WICP) for the last days of life was developed for use in all care settings across Wales.⁴ The WICP was implemented on an All-Wales basis in 2000 and used in all care settings. This work has been reported in full elsewhere.^{4,5}

The WICP has been systematically monitored using the variance reporting mechanism inherent in the integrated care pathway model.⁶⁻⁸ This national system has informed regular feedback to teams across Wales and facilitated benchmarking exercises.⁹ This level of feedback

has been a valued component of the monitoring system.¹⁰ In addition, the WICP has been annually audited against anonymised deceased patient's case-notes since 2006.¹¹

Taking account of feedback from healthcare professionals using the WICP, quality monitoring data from variance analysis and annual audit outcomes, the document has been annually reviewed to reflect current changes and recommendations in clinical practice. Major review and revision of the documentation has been undertaken twice over the 15 years of widespread use in Wales.

The recent recommendations of the Neuberger enquiry to withdraw the Liverpool Care Pathway,¹² and the subsequent work of the NHS Leadership Alliance for the Care of Dying People¹³ provided added impetus to the need for a third major review of the WICP.

This paper reports on the process of the WICP overhaul, and the resultant guidance currently being implemented across Wales.

METHODS

Prototype Document Development

A multidisciplinary working group was convened with a brief to embrace the five priorities of the NHS Leadership Alliance¹³ and produce all-Wales patient-centred guidance to support individualised care in the last days of life, to supersede the WICP.

Drawing on the strengths of the WICP a prototype document was developed by the working group, utilising the much valued prompts and 'triggers' encapsulated under 'comfort measures' (including communication, environment, symptom control, mouth care, pressure area care and elimination) and 'anticipatory prescribing'. Although, patients and those important to them are at the centre of discussion and decisions in the last days of life, this individualised approach was not always adequately evidenced in the original layout of the WICP. The prototype specifically prompted discussion and decision-making in the last days of life, and provided space to document outcomes. This evolution of the document has reduced the use of 'tick-box' or 'cookbook' medicine which became a popular criticism of integrated care pathways.¹⁴

The first iteration of the document was circulated for comments and input within the specialist palliative care community in Wales, the lead nursing groups and Macmillan GP facilitators. Simultaneously, we engaged with patient forums to explore their perspectives. They welcomed open discussion about care of the dying patient in Wales and offered valuable insights into what was expected of clinicians at this sensitive time, contributing to a more refined, second iteration of the prototype.

The next step was to canvas the views of healthcare

professionals (HCP's) looking after dying patients in other specialities and settings in Wales. Drawing on material generated by consultation with palliative care colleagues and patient groups in Wales, an electronic survey (Bristol Online Survey (BOS))¹⁵ was developed and circulated in both the specialist palliative care and generic health-care community. Response was good: 351 HCPs responded (48.7% nurses, 42.7% doctors) from all care settings in Wales. The majority were regularly caring for dying patients, and 69.2% were currently utilising the WICP.

The free text responses illustrate that formalised feedback is required to collect tangible proof of impact and structured guidance is deemed necessary and highly valued by HCPs.

"Guidance is a good baseline for the NHS and palliative care to work from whilst recognising all deaths are individual"

"(It) guides HCPs to ensure reversible causes of deterioration have been excluded, to change priority of care and focus on comfort and dignity."

"(It) gives a clear indication of the roles and responsibilities of the professionals involved, gives more inexperienced staff confidence and guidance and encourages team working."

In light of the survey responses, a third version of the prototype guidance was drawn up and circulated for comment, agreement and feasibility testing.

Feasibility Testing

Members of the working group with direct patient contact agreed to test 5 uses of the Care Decision guidance in their workplace, resulting in a pragmatic sample of n=40. Positive feedback was received from all eight participating sites, and the Care Decisions documentation was considered fit for purpose. Constructive criticism of the exact wording of phrases in the document resulted in a fourth iteration of the guidance.

Governance

Each Health Board was expected to approve the Care Decisions guidance for use in their areas. This process was led by Betsi Cadwaladr University Health Board (BCUHB). The guidance successfully underwent equality and diversity assessment and proceeded to a quality assurance appraisal which was granted. The Board endorsed a comprehensive programme of education to accompany Care Decisions implementation.

OUTCOMES

[The suite of documents and education materials can be accessed from the 'Last Days of Life' section on www.wales.palliative-care.info]

Documentation: Care Decisions

The Care Decisions guidance firmly places the patient and those

important to them at its centre. It is designed to be easily incorporated into the patient’s notes and requires the first two pages to be completed and signed by the patient’s GP, Consultant or healthcare professional in charge of their care.

The nursing plan for this episode of care can be outlined within the document and recorded fully in the nursing notes; existing nursing care plans can run alongside as appropriate. Throughout the guidance there are prompts designed to promote and document optimum care of the dying patient and those important to them.

The guidance is accompanied by a case review sheet for quality monitoring and is also supported by the provision of symptom management guidelines, a symptom assessment sheet, syringe driver chart and check list.

Case review sheet: The case review sheet is closely structured around the five priorities of care advocated by the NHS Leadership Alliance for the Care of the Dying Person (Table 1).¹³ Under each of the five priorities there are questions with a binary yes/no reply and a free text box inviting comments. HCPs are encouraged to complete a case review sheet for each patient whose

care was supported by the Care Decisions guidance.

The anonymised case review sheet is returned to the central office *via* secure fax, e-mail or post for analysis and subsequent feedback.

Symptom management guidelines: In response to a direct request from HCPs the symptom management guidelines continue to be included as a supporting resource. Although, the information contained within this document is accessible in the British National Formulary¹⁷ and the Welsh guidelines,¹⁸ its usefulness in one document directly associated with the guidelines drew universal agreement amongst colleagues. Each area has the option to include contact details for obtaining specialist palliative care advice (Table 2).

Symptom assessment sheet: Used in a similar manner to a routine observation chart, the symptom assessment sheet provides a ‘look at a glance’ summary of symptoms overtime including pain, agitation, nausea/vomiting and excess respiratory secretions or rattle that may require clinical review and subsequent input.

Table 1: Five Priorities of Care Advocated by the NHS Leadership Alliance for Care of Dying People

1	The possibility that the person may die within the coming days and hours is recognised and communicated clearly, decisions about care are made in accordance with the person’s needs and wishes and these are reviewed and revised regularly.
2	Sensitive communication takes place between staff, the person who is dying and those important to them.
3	The dying person and those important to them are involved in discussions about treatment and care.
4	The people important to the dying person are listened to and their needs are respected.
5	Care is tailored to the individual and delivered with compassion-with an individual care plan in place

Leadership Alliance for the Care of Dying People. One chance to get it right.¹³

All Wales Guidance to Support Care in the Last Days of Life: Symptom Control Guidance

Table 2: Commonly used PRN Medicines and Doses for End-of-Life Care.

Indication	Drug	Dose	Frequency	Route
Pain	Morphine	*	2-4 hrly	SC
Nausea/Vomiting	Cyclizine	50 mg	4 hrly (max 150 mg/24 hr)	SC
	Haloperidol	1.25-1.5 mg	4 hrly	SC
	Levomepromazine	6.25 mg	4 hrly	SC
Anxiety/Distress	Midazolam	2.5 or 5 mg	2 hrly	SC
Respiratory Secretions	Hyoscine hydrobromide	400 micrograms	4 hrly (max 2.4 mg / 24 hr)	SC
	Glycopyrronium	200 micrograms	4 hrly (max 1.2 mg / 24 hr)	SC

*Opioid prescriptions should be tailored according to the patient’s circumstances:
For a patient on regular opioid analgesics: calculate one sixth of the 24-hour dose for PRN use. Some patients will be able to continue with oral morphine liquid.

The chart does not carry any prescriptive directions for specific observation times thus allowing for its application in a variety of settings.

Syringe driver prescription chart: Some patients in the last days of life will require the use of regular medication *via* continuous subcutaneous infusion (CSCI) (usually delivered *via* a syringe driver or pump). The recent development and publication of an All-Wales Continuous Subcutaneous Infusion Medication Administration Record (hence referred to as ‘syringe driver prescription chart’) coincided with the implementation of the Care Decisions guidance.¹⁹

This development introduces consistency to CSCI prescriptions. In addition to the syringe driver prescription chart, the use of a local syringe driver check chart or check list is strongly advocated for safety monitoring.

Medication prescription in the community setting: There is currently no standardised All-Wales prescription chart for use in the community setting and documentation varies between geographical areas. A combined medication prescription and administration record chart on which as-needed and other regular medication could be prescribed was therefore included. This contains prompts for prescribers to include medication for common symptoms of pain, nausea/vomiting, agitation and excess respiratory secretions.

Monitoring & Evaluation

There is a current expectation of clinical teams to demonstrate a consistently high standard of quality care and evidence a continual drive to improve care at the end-of-life.²⁰

The Care Decisions project retains the established centralised system of monitoring and evaluation. This permits for a continuation of quality monitoring and, also offers an estimate of how often the Care Decision guidance is used. The annual audit of the Care Decisions guidance against anonymised deceased patient’s case-notes will continue.

The case review sheets are being returned from several areas across Wales and indicate that Priority 1 was met in 66% of cases, Priority 2 in 75%, Priority 3 in 87% and Priority 4 and 5, 93% and 86% respectively. However, this is a small sample (n=240) and outcomes at this stage should be viewed with caution.

Implementation & Education

Building on previous success implementing the WICP a “top-down, bottom-up” model was retained with a strong emphasis on local ownership and firm engagement with Health Boards. From the ‘top-down’ the Care Decisions guidance has endorsement from the Welsh Government. Progress with the changeover is centrally monitored by the Project Manager.

Education: A multidisciplinary group collaborated on the development of an education package to support the implementation of the Care Decisions guidance. Two versions were developed – a short (20-30 minute) and a long (45 minute) version. Slides, notes and teaching support tips are incorporated as well as a 3 minute case scenario video to help focus learners on the session.

An e-learning version is also in development. Anecdotal feedback on the education resource is positive, highlighting the value of a consistent approach across Wales.

DISCUSSION

This paper details the evolution of guidance to support care in the last days of life in Wales, incorporating strengths of previous work and utilising the impetus provided by the national debate on end-of-life care. It explains the function of a centralised data collection, analysis and feedback system, outlines the current implementation, future evaluation and sustainability. Superseding existing end-of-life care systems with new guidance has implications for practice and policy: A centralised quality monitoring system supports effective changeover from existing system to new guidance.

Through the process of continual quality monitoring, annual audit and review, the guidance can be kept dynamic and flexible to meet the needs of the individual patient, those important to them and the HCPs delivering care. Structured documentation provides a tangible way of evidencing the implementation of national guidance to support care in the last days of life. It enables clinical teams to demonstrate working to guidance grounded in evidence where available and best accepted care.

The Care Decisions guidance is comprised of four sides of A4 print, the Case Review Sheet and additional resources as described above. In total, this results in seven documents including the ‘as needed’ medication prescription sheet, continuous subcutaneous infusion medication administration record and check chart.

Each document is a stand-alone document however they all complement each other as a care delivery pack. There is a question about whether the documents would be best suited as a ‘one-click delivers all’ particularly in a busy care setting whereby the additional supporting documents may be overlooked.

The counter argument is that a ‘pick and mix’ format allows documents to be accessed to suit individual patient needs. To resolve the question of one document or several, we will seek a consensus view from HCPs.

The changeover from Care Priorities to Care Decisions is on-going and expected to be complete by April 2017.

The identification of barriers and enablers to the

changeover will be an important future piece of work, as will further electronic surveys of healthcare professionals to detail their satisfaction with the new guidance, supporting documents and teaching package. The collection and analysis of more Case Review sheets is expected to lead to a better understanding of care delivery in different care settings, inform feedback for teams across the country and facilitate teaching and education. Further work is needed to develop robust systems for evaluation of care in the last days of life, drive up standards and provide the very best to support each individual, their families and their health carers.

CONCLUSION

Developing a tool that advocates standardised care in the last days of life is not feasible – care at this stage needs to be individual and patient centred rather than documentation driven. However, for some healthcare professionals who lack confidence in care of the dying, prompts and clinical guidance can be invaluable to help the delivery of consistently high quality care. One of the challenges highlighted by the electronic survey was to provide a document that prompts rather than hinders thought, promotes care rather than curtails it.

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CONFLICTS OF INTEREST

The authors declare that there is no conflicts of interest.

ETHICS/RESEARCH GOVERNANCE/DATA PROTECTION APPROVALS

This work is not considered to be research and does not require ethics approval. We hold a password-protected anonymised clinical database of case review sheet outcomes, system and site secure.

REFERENCES

1. Economist Intelligence Unit. The Quality of Death: Ranking

end of life care across the world. 2015. Web site. www.eiuperspectives.economist.com/healthcare/2015-quality-death-index. Accessed May 25, 2016.

2. National Institute for Health and Care Excellence. Care of dying adults in the last days of life. 2015. Web site. www.nice.org.uk/guidance/ng31. Accessed August 2, 2017.

3. The National Council for Palliative Care. Changing Gear: Guidelines for Managing the Last Days of Life in Adults. London, 2006.

4. Fowell A, Finlay I, Johnstone R, Minto L. The Welsh collaborative care pathway project: Implementing an integrated care pathway for the dying patient in Wales. *Int J Care Coord*. 2002; 6(2): 59-62. doi: [10.1177/147322970200600202](https://doi.org/10.1177/147322970200600202)

5. Knight G, Jordan C. All-Wales Integrated care pathway project for care homes: Completing the audit cycle. *Journal of Integrated Care Pathways*. 2007; 11: 112-119. doi: [10.1258/jicp.2007.007181](https://doi.org/10.1258/jicp.2007.007181)

6. Fowell A, Finlay I, Johnstone R, Minto L. An integrated care pathway for the last two days of life: Variance analysis -what is it, how is it done, what does it show? *Journal of Clinical Excellence*. 2002; 4(2): 237-244.

7. Cheah J. Clinical Pathways: An evaluation of its impact on the quality of care in an acute general hospital in Singapore. *Singapore Med J*. 2000; 41(7): 335-346.

8. Zander K. Integrated care pathways: Eleven international trends. *Journal of Integrated Care Pathways*. 2002; 6: 101-107. doi: [10.1177/147322970200600302](https://doi.org/10.1177/147322970200600302)

9. Fowell A, Finlay I, Johnstone R, Minto L. An integrated care pathway for the last two days of life: Wales-wide benchmarking in palliative care. *Int J Palliat Nurs*. 2002; 8(12): 566-573. doi: [10.12968/ijpn.2002.8.12.10973](https://doi.org/10.12968/ijpn.2002.8.12.10973)

10. Johnstone R, Fowell A, Jones A, et al. End of life care in Wales: Evaluation of a care pathway based implementation strategy. *BMJ Support Palliat Care*. 2012; 2(2): 150-155. doi: [10.1136/bmjspcare-2011-000175](https://doi.org/10.1136/bmjspcare-2011-000175)

11. Closs S, Johnstone R, Fowell A. An All-Wales audit of the integrated care pathway for the last days of life: Establishing the audit cycle. *Journal of Integrated Care Pathways*. 2007; 11: 16-31.

12. National Institute for Health Research. *Better Endings: Right care, right place, right time*. Themed Review for the NIHR. NIHR Dissemination Centre, 2015.

13. Leadership Alliance for the Care of Dying People. One chance to get it right: Improving people's experience of care in the last few days and hours of life. Report, UK, 2014.

14. De Luc K, Kitchiner D. *Developing Care Pathways: The Handbook*. Abingdon, England: Radcliffe Medical Press; 2001.
15. Bristol Online Survey. BOS Features and pricing. Web site. www.onlinesurveys.ac.uk/features-pricing/. Accessed August 2 2017.
16. British National Formulary. Prescribing in palliative care. 2016. Web site. www.evidence.nhs.uk/formulary/bnf/current/guidance-on-prescribing/prescribing-in-palliative-care. Accessed August 2, 2017.
17. Twycross R, Wilcock A, Howard P. *Palliative Care Formulary*. 5th ed. Nottingham, UK: palliativedrugs.com; 2015.
18. Back I. *Palliative Medicine Handbook*. 3rd ed. [ebook]. 2001.
- Web site. <http://lnx.mednemo.it/wp-content/uploads/2007/01/palliative-medicine-handbook-3rd-edition.pdf>. Accessed August 2, 2017.
19. All Wales Medicines Strategy Group. Continuous subcutaneous infusion medication administration record. Web site. www.awmsg.org/docs/awmsg/medman/drug%20charts/Continuous%20Subcutaneous%20Infusion%20Medication%20Administration%20Record.pdf. Accessed August 2, 2017.
20. Public Health England. National End of Life Care Intelligence Network: Place of death. 2015. Web site. www.endoflife-care-intelligence.org.uk/data_sources/place_of_death. Accessed May 2017.