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

Helen E. Mitchell, MBCHB, MRCGP, MSc; Marlise Poolman, MBCHB, MRCP, FRCP; Rosalynde P. Johnstone, BA (Hons)

1Department of Palliative Care, Betsi Cadwaladr University Health Board, Caernarfon, Gwynedd, LL55 2YE, UK
2North Wales Centre for Primary Care Research, Bangor University, Bangor LL57 2DG, UK

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)

The WICP has been systematically monitored using the variance reporting mechanism inherent in the integrated care pathway model. This national system has informed regular feedback to teams across Wales and facilitated benchmarking exercises. This level of feedback...
has been a valued component of the monitoring system.\textsuperscript{10} In addition, the WICP has been annually audited against anonymised deceased patient’s case-notes since 2006.\textsuperscript{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,\textsuperscript{12} and the subsequent work of the NHS Leadership Alliance for the Care of Dying People\textsuperscript{13} 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 Alliance\textsuperscript{13} 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.\textsuperscript{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))\textsuperscript{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.pall-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). 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 Formulary and the Welsh guidelines, 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 over time 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

<table>
<thead>
<tr>
<th>Priority</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>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.</td>
</tr>
<tr>
<td>2</td>
<td>Sensitive communication takes place between staff, the person who is dying and those important to them.</td>
</tr>
<tr>
<td>3</td>
<td>The dying person and those important to them are involved in discussions about treatment and care.</td>
</tr>
<tr>
<td>4</td>
<td>The people important to the dying person are listened to and their needs are respected.</td>
</tr>
<tr>
<td>5</td>
<td>Care is tailored to the individual and delivered with compassion—with an individual care plan in place.</td>
</tr>
</tbody>
</table>

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

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

<table>
<thead>
<tr>
<th>Indication</th>
<th>Drug</th>
<th>Dose</th>
<th>Frequency</th>
<th>Route</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>Morphine</td>
<td>*</td>
<td>2-4 hrly</td>
<td>SC</td>
</tr>
<tr>
<td>Nausea/Vomiting</td>
<td>Cyclizine</td>
<td>50 mg</td>
<td>4 hrly (max 150 mg/24 hr)</td>
<td>SC</td>
</tr>
<tr>
<td></td>
<td>Haloperidol</td>
<td>1.25-1.5 mg</td>
<td>4 hrly</td>
<td>SC</td>
</tr>
<tr>
<td>Anxiety/Distress</td>
<td>Levomepromazine</td>
<td>6.25 mg</td>
<td>4 hrly</td>
<td>SC</td>
</tr>
<tr>
<td>Respiratory Secretions</td>
<td>Hyoscine hydrobromide</td>
<td>400 micrograms</td>
<td>4 hrly (max 2.4 mg / 24 hr)</td>
<td>SC</td>
</tr>
<tr>
<td></td>
<td>Glycopyrronium</td>
<td>200 micrograms</td>
<td>4 hrly (max 1.2 mg / 24 hr)</td>
<td>SC</td>
</tr>
</tbody>
</table>

*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.\textsuperscript{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.\textsuperscript{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 in-
dividual and patient centred rather than documentation driven.
However, for some healthcare professionals who lack confi-
dence 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.

FUNDING
The corresponding author’s substantive post (All-Wales End-of-
Life Care Programme Manager) is funded by the Welsh Govern-
ment.

ACKNOWLEDGEMENTS
We are grateful for the input of all members of the Task and Fin-
ish Group (for the review of the WICP) as well as the scrutiny by
the All-Wales Palliative Medicine and All-Wales Palliative Care
Lead Nurse Groups.

Thanks are also due to the various members of the pa-
tient representative groups in Wales and all colleagues who gave
freely of their time to contribute to the development and evolu-
tion of the Care Decisions Guidance.

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.eiuper-
2. National Institute for Health and Care Excellence. Care of dy-
3. The National Council for Palliative Care. Changing Gear: Guide-
lines for Managing the Last Days of Life in Adults. Lon-
don, 2006.
4. Fowell A, Finlay I, Johnstone R, Minto L. The Welsh collab-
orative care pathway project: Implementing an integrated care
pathway for the dying patient in Wales. Int J Care Coord. 2002;
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
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 Excel-
7. Cheah J. Clinical Pathways: An evaluation of its impact on the
quality of care in an acute general hospital in Singapore. Singa-
8. Zander K. Integrated care pathways: Eleven international
doi: 10.1177/147322970200600302
pathway for the last two days of life: Wales-wide benchmarking
Wales: Evaluation of a care pathway based implementation
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.
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.


