



Royal College of
General Practitioners

' End of Life Care Review' Case Review Audit

Author: Primary Care Quality and Information Service

Date: January 2013

Version: 1

Status: Final

Intended audience: Public (Internet) / NHS Wales (Intranet) / Public Health Wales (Intranet)

Purpose and summary of document:

This document is for use by general practices who are engaged in providing services for patients registered with their practice who required **end of life care**. The purpose of this quality improvement toolkit is to support practices to review and improve where necessary the care provided to people in the last stages of life.

The aim of this toolkit is to improve the recording of clinical information to support End of Life care. It will encourage practitioners to take a proactive approach to caring for people who are nearing end of life. It will provide the user with a summary of the evidence directing the safe provision of service, the organisational components of service provision and a schedule of patient review criteria to compare and reflect on the service delivery and treatment against national evidence based criteria.

The criteria presented are considered to be key criteria associated for the care of all patients at the end of life

'How people die remains in the memory of those who live on'
(Dame Cicely Saunders 1918-2005)

Publication / distribution:

- Publication in PHW Document Database (Primary Care Quality and Information service)
- Link from PHW e-Bulletin

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Preface

Quality improvement toolkits

The Primary Care Quality and Information Service (PCQIS) produces evidence based quality improvement toolkits to assist practices in collating and auditing information regarding the processes and outcomes of their care to patients. This toolkit has been produced in cooperation with the Royal College of General Practitioners Wales (RCGPWales) End of Life Care Network.

They should be seen as good practice guidance and may cover areas of data collection that some or even all practices may not be recording at this stage. It is not expected that all the criteria within these audits will necessarily be achieved in year one but the toolkits can guide practices as to what data they should be recording for the future.

Toolkits are not designed for performance monitoring. HB's considering using these toolkits should first discuss with their constituent practices how the toolkits might be used for locality audits.

You can access other quality improvement toolkits that support enhanced services and National Service Frameworks from the Public Health Wales website:

Intranet <http://howis.wales.nhs.uk/sitesplus/888/page/34030>

Internet <http://www.wales.nhs.uk/sitesplus/888/page/45127>

Setting the Scene - Case Review Audit

Individual case review should be conducted once a death of a patient has occurred. Each case is presented for comment **one month** after the care episode is complete. It is recommended that it is conducted within a multi-professional meeting with the wider team involved in review.

Suggestions for developing practice often come out of case reviews. Thus there should be a mechanism for systematic action planning (see Appendices document @ <http://www.wales.nhs.uk/sitesplus/888/page/59780>)

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Background

The World Health Organization (WHO) defined palliative care as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Planning for care at the end of life should be responsive to patient choice regarding place of care and place of death. Palliative and end of life care are integral aspects of the care delivered by any health or social care professional to those living with and dying from any advanced, progressive or incurable condition.

Palliative care is not just about care in the last months, days and hours of a person's life, but about ensuring quality of life for both patients and families at every stage of the disease process from diagnosis onwards. A palliative care approach should be used as appropriate alongside active disease management from an early stage in the disease process. Palliative care focuses on the person, not the disease, and applies a holistic approach to meeting the physical, practical, functional, social, emotional and spiritual needs of patients and carers facing progressive illness and bereavement ^{1, 2, 3}

Definition of end of life care ¹

The following definition of end of life is taken from the GMC guidance: Treatment and care towards the end of life

Patients are 'approaching the end of life' when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with:

- Advanced, progressive, incurable conditions
- General frailty and co-existing conditions that mean they are expected to die within 12 months
- Existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- Life-threatening acute conditions caused by sudden catastrophic events.

Palliative care

The holistic care of patients with advanced, progressive, incurable illness, focused on the management of a patient's pain and other distressing symptoms and the provision of psychological, social and spiritual support to patients and their family. Palliative care is not dependent on diagnosis or prognosis, and can be provided at any stage of a patient's illness, not only in the last few days of life. The objective is to support patients to live as well as possible until they die and to die with dignity.

End stage

This can be considered as the final period, or phase in the course of a progressive disease leading to a patient's death.

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Purpose of end of life care reviews^{1, 2, 3, 4, 5, 9,12}

About 1% of the population die every year, of which almost two thirds are aged over 75. The large majority of deaths follow a period of chronic illness such as heart disease, cancer, stroke, chronic respiratory disease, neurological disease or dementia. Most deaths (58%) occur in NHS hospitals even though the majority of patients would prefer to die at home.

The Palliative Care Strategy in Wales recognises the importance of the general practitioner and the primary care team in providing care to patients at home. The Royal College of General Practitioners endorses the need for audit of end of life care.

The overall intention of this **end of life care review** is to improve the dignity and care of patients in the final stages of their life and to ensure comfort, good control of pain, with fears addressed and causes of distress acknowledged and ameliorated as much as possible.

This review will enable practices to check where patients died, if it was their preferred place of death and which services/resources they utilised.

This review suggests looking at **all deaths** to consider whether, with the benefit of hindsight, it could have been recognised that the person had end of life care needs.

It is recommended that the Primary Health Care Team (PHCT) look at the percentage of patients on their palliative care register who have a non-malignant diagnosis. Cancer patients have traditionally been recognised as having end of life care needs so this is a new way of thinking for diagnoses. Consider patients with the following:

- Cancer
- COPD
- Neurological disorders
- Chronic heart disease
- Renal Failure
- Dementia
- Those with multiple morbidities.

The Department of Health Quality Markers and Measures for end of life care recommends all practices audit their care and create an action plan using an audit tool⁵ (see appendix B) <http://www.wales.nhs.uk/sitesplus/888/page/45127>

6. Aim

To ensure patients at the end of their lives receive high-quality treatment and care that supports them to live as well as possible until death, and to approach death with dignity.

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Objectives

- To improve identification of patients nearing the end of life
- To enhance advance care planning discussions and the documentation of people's preferences in care
- To ensure more patients die in their preferred place of death
- To improve provision of anticipatory care to terminally ill patients
- To ensure that the physical, psychosocial and spiritual needs of terminally ill patients are recognised, considered and met

7. Methodology

To aid practitioners improve the data quality within practice. PCQIS suggests over the next 3-6 months, the practice starts to record **every death** and review the deaths within a 2-4 week period before patient's medical record are returned to Contractor Services.

N.B - Contractor Services action death notifications within 48 hours of receipt with an average time following death of 18 days practices would receive the death notification from Contractor Services 24 hours later, via the Registrar of Deaths and Office for National Statistics (ONS) process.¹²

GP practices are requested to return patient's medical record to Contractor Services within 14 days of request.¹²

To complete this audit, it would be advisable to involve the multidisciplinary team responsible for all "end of life care" patients.

- 7a** First complete the **Practice Organisation review form** (page 8) which looks at organisational issues relating to the end of life care provided. The review sheet sets out a series of questions based on headings specified and reflects criteria suggested by the latest evidence.
- 7b** Complete the individual patient **Case review sheet** (page 10) and reflect on findings, making use of the action plan to record necessary changes needed.
- 7c** Practices should use the audit results (See page 12) as the basis of a discussion by the PHCT. Completion of the audit enables General Practice teams to reflect on the patient journey, identifying good practice and opportunities for service improvement.

NB; consider each case in terms of:

- Organisational matters
- Knowledge, skills and performance for individuals and practice
- Safety and quality
- Communication, partnership and teamwork
- Maintaining trust

7d what changes have been agreed?

- for you individually
- for the team

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Search strategy

Target population search to be carried out on all deaths; target population can be accessed by entering the following commands into the practice computer system:

- R21.. [D]Sudden death, cause unknown
- 94F.. Unexpected death
- R212. [D]Death less than 24 hours from onset of illness
- R213. [D]Unattended death
- 9Ng7. On end of life care register

Patient records may need to be to be looked at manually (i.e. nursing notes, care plans, dying pathway documentation), which maybe in patient home/or DN clinic (This could be accessed by an administrative person who could then fill in the case review sheet ready for clinical assessment and reflection).

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8. Practice organisation ^{1, 2,3,4,5,6,7,8,9,10,11,12}

Area for review	Service Provision - delivery of effective end of life care	Achieved	Not Achieved	Comments
Practice Register	The practice has an up to date and accurate end of life care register (EOLC)			
Communication	<p>The practice holds monthly multidisciplinary team (MDT) meetings with all staff to discuss all cases and keeps a record of such discussions.</p> <p>The Practice has access to individual patient record folders that are pre-populated with local contact numbers (e.g. OOH numbers, District Nursing contact numbers, pharmacies etc).</p> <p>The practice has electronic copies of palliative care prescribing guidance.</p> <p>The practice accesses palliative care information web pages to give advice / provide information for practices/other professionals involved in end of life.</p>			
CPD	<p>The practice allows for protected time for learning sessions to facilitate palliative care learning for practice, District Nursing Teams, and other community nurses.</p> <p>At least one member of the PHCT attends an external EOLC training event annually.</p> <p>The PHCT reflect and audit following the death of those patients within inclusion criteria within one month.⁶</p>			
EOLC Co-ordinator	The practice has a named coordinator lead for Palliative / End of life care. ^{3,4}			

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Area for review	Service Provision- delivery of effective end of life care.	Achieved	Not Achieved	Comments
Last Stages Of life	<p>Those patients who are discharged from hospital to "die at home" are visited by a GP from the practice</p> <p>The practice ensures that patients in the last days of life are entered onto the all Wales Integrated Care priorities for the Last Days of Life (ICP) http://wales.pallcare.info/index.php?p=sections&sid=53</p>			
Infusion Equipment	<ul style="list-style-type: none"> • Strategies in place for 24 hour access to syringe drivers • Care and storage of syringe driver equipment discussed with family 			
Out of hours (OOH)	<ul style="list-style-type: none"> • 'Just in Case' Box of medication are available⁹ • Instructions to the patient/family as to who to call out of hours in event of them needing support are available • There is a system of notifying OOH (an agreed flagging form as in Appendix D can be helpful) 			
Immediately after Death	<p>The practice has systems in place to allow for:</p> <ul style="list-style-type: none"> • Notifying DN, OOH when deaths occur • Inform families and Carers as to what to do / who to contact • Consider the bereavement support needs of children in the family http://www.cruse.org.uk/Children.html • Signpost families for bereavement support http://www.crusebereavementcare.org.uk/ • Advice on arrangements for burial and cremation, reflecting the cultural and spiritual needs of the family 			

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9. Individual patient retrospective case review Sheet ^{1, 2, 3, 4, 5, 6,7,8,9,11,12}

Inclusion Criteria - All patients that died within the last month- Identify those whose death could have been predicted ie people with the following diagnoses: Cancer, Heart Failure, COPD, Renal Failure, Neurological Disorders eg MND, MS, Stroke, Dementia.

Exclusion Criteria: Unexpected trauma

PT ID	All ages identified with incurable illness in the palliative phase	Yes	No	Comments
	Detecting and identifying patients early Was the patient on the primary care practice Palliative Care Register six months prior to death			
	Was the patient on the primary care practice palliative care register at the time of death			
	Preferred place of death discussed and recorded			
	Anticipatory care considered and recorded			
	The patient or carer received a completed copy of their care plan			
	DS1500 form completed			

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PT ID	Last days of life	Yes	No	Comments
	Coordinating care in last days of life - Was the patient entered onto the all Wales Integrated Care priorities for the Last Days of Life (ICP) http://wales.pallcare.info/index.php?p=sections&sid=53			
	Was a home visit made by a GP at the practice, before the patient was entered onto the all Wales Integrated Care priorities for the Last Days of Life (ICP)			
	Before the patient entered the all Wales Integrated Care priorities for the Last Days of Life did they meet at least two of the following criteria; Bed bound / Semi-Comatose / Only able to take sips of fluid / No longer able to take tablets			
	OOH informed of patient entering onto the all Wales Integrated Care priorities for the Last Days of Life (See appendix D)			
	Ongoing management - PRN (Only when required) medications available for the following symptoms in anticipation of; Pain / Nausea & Vomiting / Agitation / Respiratory Tract Secretions			
	Were there any unplanned/unscheduled admissions during the final days?			
	All Wales DNACPR Orange form (signed) present in patient notes http://wales.pallcare.info/index.php?p=sections&sid=53			
	DNACPR discussed with Next of kin			
	DNACPR confirmed from Medical notes			
	Patient assessment content; Physical needs assessed and documented			
	Social needs assessed and documented			
	Mental state assessed and recorded			
	Spiritual needs discussed and recorded (i.e. signpost family for spiritual guidance if required)			
	After Death	Yes	No	Comments
	The preferred place of death was achieved			
	The practice offered bereavement support following death of family member			
	Death was discussed at the following MDT meeting			
	The family and carers were informed as to what to do / who to contact when death occurred http://www.patient.co.uk/showdoc/145/			

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10. Clinician consideration^{3, 7}

Reflective learning encompasses both good and bad deaths and enables health care Professionals to link their professional development to practical outcomes allowing them to use new knowledge and skills in future practice. Reflective learning helps to establish and maintains good team work.

It is important that the practice seeks out opportunities for multi-disciplinary education. Through such reflection the educator has an opportunity to harness a rich diversity of knowledge and stimulate discussion about different approaches to palliative and end of life care.

The team should consider asking questions that offer some outcome data.

Very well **reasonably well** **OK** **fairly badly** **Very badly**
5 **4** **3** **2** **1**

1. How well did the practice support this patient towards the end of life?

5 **4** **3** **2** **1**

2. How well did the practice support the carers/family during the last stages of life?

5 **4** **3** **2** **1**

3. How well did the practice control symptoms during the last days of life?

5 **4** **3** **2** **1**

4. Did the practice provide/signpost bereavement support to carers?

5 **4** **3** **2** **1**

5. How well did the practice liaise as a team

5 **4** **3** **2** **1**

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