



High quality and choice of end of life care



Foreword

The first of April 2013 saw the successful completion of the transfer of Public Health Services from the Primary Care Trusts to the County Council, and the Health and Wellbeing Board, established in shadow form in 2011, take on its full statutory powers and duties.

The Health and Wellbeing Board has developed its first Health and Wellbeing Strategy – *Healthy Lives, Healthy People, The East Sussex Health and Wellbeing Strategy 2013-2016* – which aims to protect and improve people’s health and wellbeing and reduce inequalities. The Strategy sets out the seven key priorities for improvement over the next three years:

1. The best possible start for all babies and young children
2. Safe, resilient and secure parenting for all children and young people
3. Enabling people of all ages to live healthy lives and have healthy lifestyles
4. Preventing and reducing falls, accidents and injuries
5. Enabling people to manage and maintain their mental health and wellbeing
6. Supporting those with special educational needs, disabilities and long term conditions
7. High quality and choice of end of life care

These priorities are areas where the Board can make a real difference and the strategy sets out how this will be achieved through the commissioning of services, joint working and collective action.

The Annual Report of the Director of Public Health 2013/14 was produced to inform delivery of the Health and Wellbeing Strategy. Whilst the full Annual Report covers all seven priority areas, a series of booklets have also been produced which focus on each of the priority areas in turn. Each booklet reproduces what is contained in the Annual Report for that area.

This booklet presents the results for priority 7: High quality and choice of end of life care.

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Chapter 1: Introduction

The Director of Public Health is required by statute to prepare and publish an annual report. This year's report provides the evidence to help commissioners identify the interventions that will deliver the priorities which have been agreed in the East Sussex Health and Wellbeing Board's Health and Wellbeing Strategy for 2013-2016 "Healthy Lives, Healthy People".

The report presents the results from a series of rapid evidence and literature reviews aligned to the seven priority areas identified in Healthy Lives, Healthy People and the recommendations will help service commissioners to ensure that they make the best investment of the resources they have available and to weigh the return on that investment against other competing priorities.

For each of the seven priority areas, sub-topics have been identified which are important for delivery. Recommendations from the evidence reviews have been included in the appendices, and the full evidence review reports are included on the East Sussex Joint Strategic Needs Assessment website www.eastsussexjsna.org.uk.

To make the recommendations more easily accessible a series of booklets have been produced. Each booklet focuses on one of the priority areas in Healthy Lives, Healthy People, and reproduces what is contained in the full annual report for that area, including all the recommendations contained in the appropriate appendix.

Booklet 1: The best possible start for all babies and young children

Booklet 2: Safe, resilient and secure parenting for all children and young people

Booklet 3: Enabling people of all ages to live healthy lives and have healthy lifestyles

Booklet 4: Preventing and reducing falls, accidents and injuries

Booklet 5: Enabling people to manage and maintain their mental health and wellbeing

Booklet 6: Supporting those with special educational needs, disabilities and long term conditions

Booklet 7: High quality and choice of end of life care

Commissioners can use the booklets to prioritise the key recommendations for implementation. Recommendations should be prioritised where they:

- are not part of current practice;
- highlight the need for practice to change;
- require retraining or the development of new skills;
- require implementation by a broad range of agencies or across a range of settings
- may be viewed as potentially contentious or difficult to implement for other reasons.

The Health and Wellbeing Strategy Action Plan

Healthy Lives, Health People is supported by an action plan setting out high level actions, outcomes, indicators and targets including those aimed at ‘narrowing the gap’ between the best and worst performing areas in the county. Table 1.1 presents the targets and indicators for priority area 7: High quality and choice of end of life care.

The Structure of this Booklet

This booklet outlines the approach taken to review the literature and evidence, identifies the sub-topics that are important for delivery, presents some of the key facts and figures for and then identifies evidence based recommendations for implementation.

The full evidence review report for this priority area is included on the East Sussex Joint Strategic Needs Assessment website **www.eastsussexjsna.org.uk**.

Table 1.1 The Health and Wellbeing Strategy Action Plan: Priority Area 7 – High quality and choice of end of life care

OUTCOMES	ACTIONS AND OUTPUTS	OBJECTIVES	STRATEGIC OUTCOMES
Priority 7: High quality and choice of end of life care			
<p>More people who are approaching the end of life being cared for and dying in their preferred place of care and death and to receive the highest standards of end of life care in any setting</p>	<ul style="list-style-type: none"> • Roll out the delivery of the end of life care pathway (from advanced care planning to bereavement support) throughout all public, private and voluntary and community sector health and care providers • Continue End of Life Care training and workforce development for health and care staff and volunteers working in community, health and care settings 	<ul style="list-style-type: none"> • More people identified as approaching end of life have an advanced care plan • Fewer people identified as approaching end of life dying in hospital • Staff providing end of life care in community, health and care settings meet the national end of life care core competencies and occupational standards 	<p>7.1 More people identified at their residence. <u>Indicator definition:</u> 7.1.1 Deaths at usual place of residence - Local Authority indicator as it does not include deaths recorded on Electronic Palliative Care Coordination Systems can be recorded as place of care. 7.1.2 Proportion of people dying in hospital. Information about people dying in hospital is available from the <u>Baseline:</u> 7.1.1 (2012/13 at Quarter 4) = 45.3% Hastings and Rother PCCs hospices in the area. 7.1.2 2013/14 = zero% Target by 2016: 7.1.1 Increase by 1% each year to 46.3% HWLH CCG, and 45.3% HWLH CCG. 7.1.2 2013/14 Identify people who are not recorded on EPaCCS; 2014/15 upload to EPaCCS; 2015/16 upload to EPaCCS; 2016/17 upload to EPaCCS. NB: Targets for EHS and Rother PCCs will be available from 2016/17. 7.2 Improve the experience of people approaching the end of life. Indicator definition: Workforce development available resources and training. This is completed based on the <u>Baseline:</u> until 2014/15, people who are not recorded on EPaCCS; 2014/15 upload to EPaCCS; 2015/16 upload to EPaCCS; 2016/17 upload to EPaCCS. out the end of life care pathway. This is completed based on the <u>Baseline:</u> until 2014/15, people who are not recorded on EPaCCS; 2014/15 upload to EPaCCS; 2015/16 upload to EPaCCS; 2016/17 upload to EPaCCS. inclusion in this action plan. <u>Baseline:</u> This is a new indicator. <u>Target by 2016:</u> TBC due to the complexity of the indicator.</p>

ME INDICATORS

ified as approaching end of life are cared for and die in their usual place of

place of residence divided by all deaths (usual residence includes home, care
ty and non-Local Authority - and religious establishments). [This is an interim
t provide information about patient choice and quality of care. When an
are Coordination System (EPaCCS) (7.1.2 below) is in place, preferences of care
rt of the national information standard ISB 158].
oulation served by GPs and Out Of Hours services that have access to
ople approaching end of life on an EPaCCS or other coordination system.

er 1) England average 42.9%; East Sussex Downs and Weald PCT area 47.3%;
CT area 42.3% plus 5% to account for the above national average deaths in

(this is a new initiative to be launched during 2013/14).

ach year reaching 50.3% at Quarter 4 2015/16 for both EHS CCG and
s in H&R CCG.

a system and host for EPaCCS by Q4; 2014/15 = 40% EOLC patient data
2015/16 = 75%.

nd HWLH CCGs are the same based on historical 2012 PCT data. CCG level data
2014.

ience of care for people at the end of their lives.

ork is underway with providers to identify and develop mechanisms, within
nd capacity, to record carers and families experience of end of life care. Once
elines and targets can be established. Whilst reporting would not commence
s experience of end of life care will be impacted by strategic actions to roll
e pathway and to develop the workforce, making this measure relevant for
n plan.

v measure.

uring 2013/14.

Chapter 2: Evidence based commissioning

2.1 The approach – identifying the evidence

Within each of the seven priority areas of the Health and Wellbeing Strategy several sub-topics were identified as important for delivery. These were reviewed for evidence to support health and social care interventions and services.

The reviews focused on systematic reviews and meta-analyses, but where there was a lack of evidence, randomised controlled trials were also included. Each review aimed to identify the most important and relevant message supported by the scientific literature. They deliver a summary of clear and concise evidence statements based on the 5-10 most recent and relevant systematic reviews or meta-analyses.

Table 2.1: Sub-topics for the overall literature review of priority area 7: High quality and choice of end of life care

Priority area	Sub-topic
High quality and choice of end of life care	a. Interventions to increase the number of people identified as approaching end of life
	b. Interventions to increase the number of people identified as approaching end of life with advanced care plans
	c. Interventions to promote the number of people dying in their preferred place of care and reduce the number dying in hospital
	d. Interventions to promote end of life care staff training
	e. Interventions to support people who are bereaved

Evidence was classified based on the Scottish Intercollegiate Guidelines Network (SIGN) methodology. These reviews did not include a full systematic assessment of study quality (Table 2.1). Perceived levels of bias and probabilities of causal relationships were scored based on an assessment of each source’s methodology. Scorings were indicative rather than definitive.

Table 2.2: Study Quality Classification

1++	High quality meta-analyses, systematic reviews of Randomised Controlled Trials, or RCTs with a very low risk of bias.
1+	Well-conducted meta-analyses, systematic reviews, or RCTs with a low risk of bias.
1-	Meta-analyses, systematic reviews, or RCTs with a high risk of bias.
2++	High quality systematic reviews of case control or cohort or studies. High quality case control or cohort studies with a very low risk of confounding or bias and a high probability that the relationship is causal.
2+	Well-conducted case control or cohort studies with a low risk of confounding or bias and a moderate probability that the relationship is causal.
2-	Case control or cohort studies with a high risk of confounding or bias and a significant risk that the relationship is not causal.
3	Non-analytic studies, e.g. case reports, case series.
4	Expert opinion.

The recommendations for each topic were classified using a system based on the overall quality of the evidence. Recommendations graded ‘A’ are based on the highest quality evidence and those graded ‘D’ the lowest.

Table 2.3: Recommendation Strength Classification

A	At least one meta-analysis, systematic review, or RCT rated as 1++, and directly applicable to the target population; or a body of evidence consisting principally of studies rated as 1+, directly applicable to the target population, and demonstrating overall consistency of results.
B	A body of evidence including studies rated as 2++, directly applicable to the target population, and demonstrating overall consistency of results; or extrapolated evidence from studies rated as 1++ or 1+.
C	A body of evidence including studies rated as 2+, directly applicable to the target population and demonstrating overall consistency of results; or extrapolated evidence from studies rated as 2++.
D	Evidence level 3 or 4; or extrapolated evidence from studies rated as 2+.

2.2 Commissioning prioritisation

This booklet aims to provide commissioners and multi-agency partnerships with a checklist against which commissioning plans and strategies can be compared to ensure they are based on current best evidence.

The evidence review includes some interventions that are well established within local services. However, it is recommended that commissioners and multi-agency partnerships review the full list of recommendations against strategies.

A process of prioritisation and building recommendations into work plans is recommended using the following criteria to identify interventions which:

- are not part of current practice;
- highlight the need for practice to change;
- require retraining or the development of new skills;
- require implementation by a broad range of agencies or across a range of settings; and
- may be viewed as potentially contentious or difficult to implement for other reasons.

Chapter 3: High quality and choice of end of life care

Focus on

- 3.1 Interventions to increase the number of people identified as approaching end of life
- 3.2 Interventions to increase the number of people identified as approaching end of life with advanced care plans
- 3.3 Interventions to promote the number of people dying in their preferred place of care & reduce the number dying in hospital
- 3.4 Interventions to promote end of life care staff training
- 3.5 Interventions to support people who are bereaved

There are around 6,000 deaths per year in East Sussex. Around 2,200 per year in the Eastbourne, Hailsham and Seaford CCG area; 2,300 in the Hastings and Rother CCG area; and, around 1,500 per year in the High Weald Lewes Havens CCG area

3.1 Key facts and figures: people identified as approaching end of life

- People are approaching the end of life when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:
- advanced, progressive, incurable conditions;
 - general frailty and coexisting 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; and
 - Life threatening acute conditions caused by sudden catastrophic events.

In 2011/12 there were 1170 people on GP palliative care registers across East Sussex, an increase of 40% on the 2010/11 figure of 835. The increase can be explained by better recording in general practice. However, it also demonstrates significant demand.

Table: 3.1: Number of patients recorded on GP reported palliative care registers, Clinical Commissioning Groups 2010/11 and 2011/12

Clinical Commissioning Group	2010/11	2011/12
Eastbourne Hailsham Seaford	342	404
Hastings & Rother	279	465
High Weald Lewes Havens	214	301

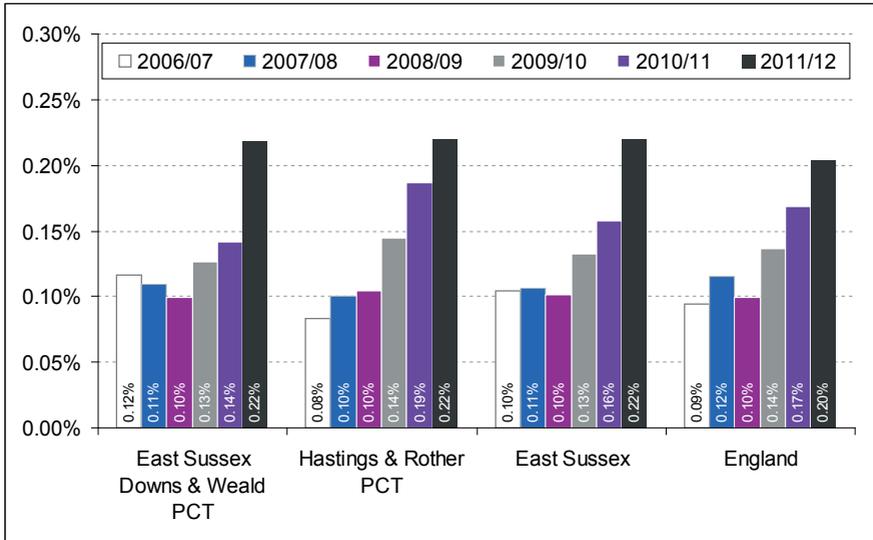
Source: Quality Outcomes Framework 2011/12, Health & Social Care Information Centre www.hscic.gov.uk/qof

3.2 Key facts and figures: advanced care plans

Advanced care planning is a process of discussion between an individual and their care providers to make clear a person's wishes. Carers, family and friends may also be involved

Figure 3.1 illustrates the increasing numbers of patients on GP palliative registers requiring end of life care, an indication of increasing need for advanced care plans

Figure 3.1: GP reported palliative care registers, proportion of patients on palliative care register, Primary Care Trusts, 2006/07 to 2011/12



Source: Quality Outcomes Framework 2011/12, Health & Social Care Information Centre www.hscic.gov.uk/qof

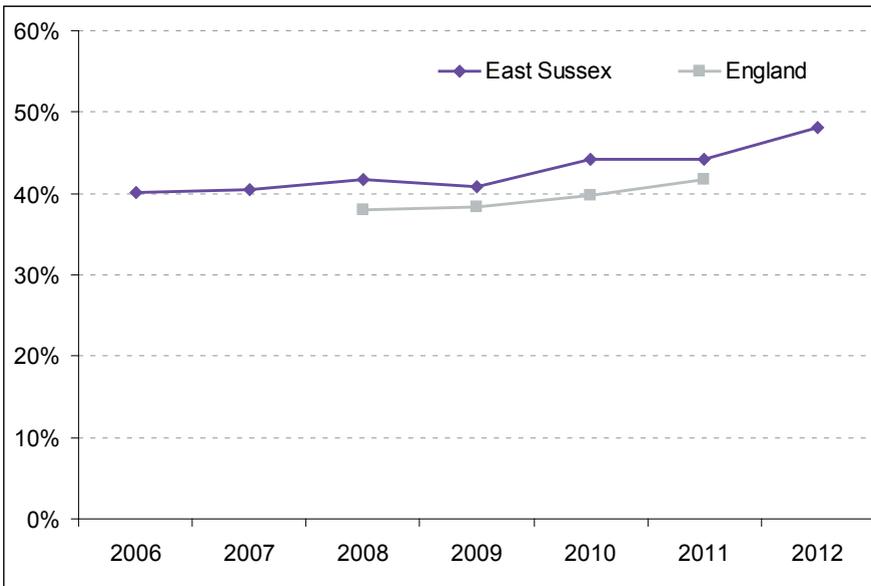
3.3 Key facts and figures: people dying in their preferred place of care

For people identified as approaching end of life, place of death is an important quality measure. The majority of people would prefer to die in their usual place of residence if circumstances allowed.

In 2012, 48% of deaths for East Sussex residents were in their usual place of residence and 43% of deaths were in hospital. In Hastings and Rother CCG 45% of deaths were in the usual place of residence and the percentages were 51% for Eastbourne, Hailsham and Seaford CCG and 48% for High Weald Lewes and Havens CCG.

Figure 3.2 shows an improvement in this indicator in both East Sussex and England.

Figure 3.2: Percentage of deaths at usual residence, 2006 to 2012



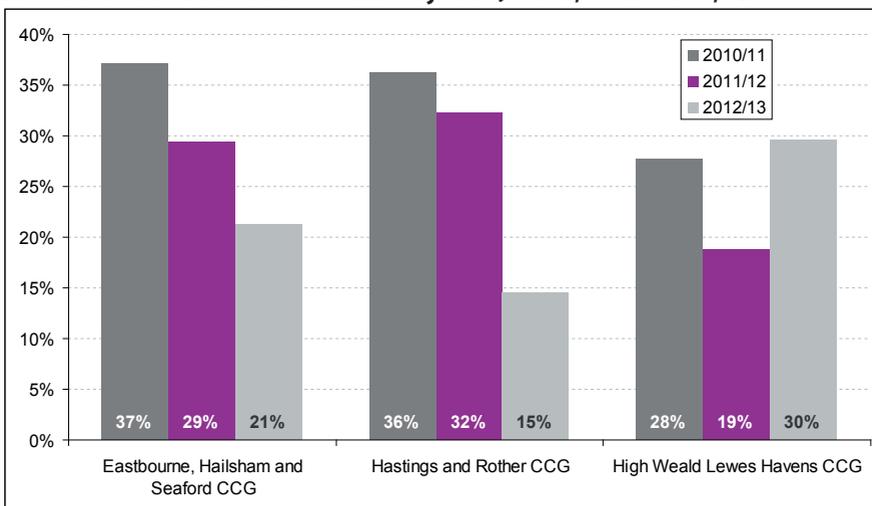
Source: Death registrations, Office for National Statistics

3.4 Key facts and figures: staff training and end of life care

Care of the dying requires not only substantial technical knowledge and clinical skill in assessing and adapting care to an individual's rapidly changing needs, but above all it needs excellent communication skills. These are an essential competence for doctors and nurses, and yet clinicians are sometimes particularly poor at dealing with discussions about a person's impending death. Unless there has been good communication between staff and relatives or carers, unnecessary misunderstandings can arise. For example, cessation of routine observations of temperature, blood pressure and pulse may appear as though routine nursing care has stopped. To many relatives, an unexplained cessation of observations means there is a lack of care. Evidence suggests some hospital doctors, no matter how senior, sometimes see communication as time consuming and an optional extra, rather than at the heart of effective care. This is very disturbing.¹

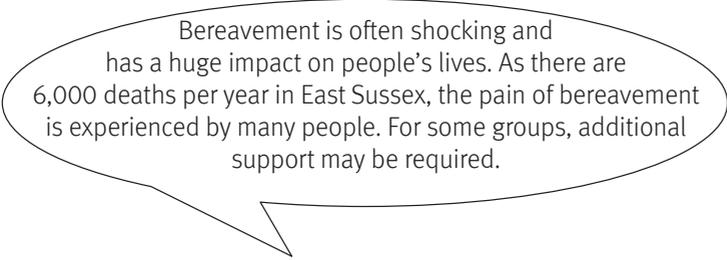
A significant percentage of palliative care hospital admissions end in death in hospital (Figure 3.3).

Figure 3.3: Percentage of palliative care hospital admissions that ended in death by CCG, 2010/11 to 2012/13

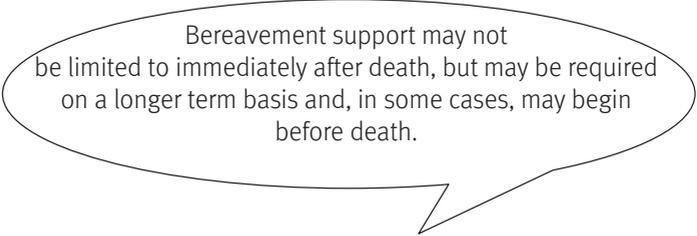


Source: Local East Sussex SUS extracts, East Sussex Public Health Intelligence Team

3.5 Key facts and figures: supporting people who are bereaved



Bereavement is often shocking and has a huge impact on people's lives. As there are 6,000 deaths per year in East Sussex, the pain of bereavement is experienced by many people. For some groups, additional support may be required.



Bereavement support may not be limited to immediately after death, but may be required on a longer term basis and, in some cases, may begin before death.

Recommendation: commissioners and multi-agency partnerships delivering in this area should review current commissioning plans and strategies against evidence recommendations laid out in Chapter 4. Where gaps or weaknesses are identified interventions for implementation should be prioritised using criteria outlined in Chapter 2.

References

Parry et al(2013) Rapid evidence review: pathways focused on the dying phase in end of life care and their key components. Sue Ryder Care Centre for the Study of Supportive, Palliative and End of Life Care, National End of Life Programme and University of Nottingham. <https://www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients>

Chapter 4: Evidence based recommendations for priority area 7

The objective of this section is to make evidenced based recommendations that support commissioners with a robust basis for decision making.

Recommendations are based on evidence from systematic reviews and meta-analyses. Scoring of recommendations is based on the SIGN methodology as set out in Chapter 2. Recommendations graded 'A' are based on the highest quality evidence and those graded 'D' the lowest. These reviews were carried out at a specific point in time and we acknowledge there are further caveats commissioners must take into consideration:

- NICE guidance is being updated on a continuous cycle, and some of the evidence presented here may not have been reviewed by NICE at this time. Commissioners need to ensure interventions do not conflict with current NICE guidance.
- East Sussex CCGs operate a 'Low Priorities Procedures' process whereby some procedures are not ordinarily commissioned and requests for treatment are referred to an 'individual treatment panel'. It is important to recognise that the agreed processes should be followed for these interventions.
- Locally, new pathways to treatment for patients for a wide range of conditions are being developed by GPs, commissioners and secondary care clinicians. It is important to ensure agreed treatment pathways are followed.

It is recommended that commissioners review the entire evidence base set out in the evidence review for this priority area, but that service planning focuses on those issues highlighted in this recommendations section.

RECOMMENDATION NUMBERS LISTED ARE THOSE FROM THE FULL EVIDENCE REVIEW FOR THIS PRIORITY AREA. FULL EVIDENCE REVIEWS ARE AVAILABLE ON THE EAST SUSSEX JOINT STRATEGIC NEEDS ASSESSMENT WEBSITE WWW.EASTSUSSEXJSNA.ORG.UK

2.2 Recommendations for interventions to increase the number of people identified

This evidence review recommends:

Intervention	
Commissioner	
2.2.1	Promote and commission services that identify people approaching the end of their life.
2.2.2	Ensure people approaching the end of their life are identified at the time of diagnosis.
Service provider	
2.2.3	Service providers should ensure that systems are in place to identify people approaching the end of their life.
Health and social care professional	
2.2.4	Encourage health and social care professionals to identify people approaching the end of their life.
2.2.5	Ensure clinicians caring for patients with terminal cancer are aware of the signs and symptoms of end of life, and the importance of identifying patients for achieving a good death.
Decision support tools for assisting clinicians with timely identification	
Encourage:	
2.2.6	clinicians to use decision support tools with timely identification of patients approaching the end of their life.
2.2.7	health professionals to identify those patients who may be nearing the end of their life.
Care Register	
2.2.8	Promote evidence based strategies to include more patients on the Care Register.
2.2.9	Consider using the question: “Would you be surprised if this patient died? What could be done to be prepared just in case this occurred?”
2.2.10	Consider using prognostic indicator guidance to increase the chance of identifying patients who are approaching the end of their life. Prognostic Indicator Guidance (RCGP website).
2.2.11	Encourage health professionals to use the RADboud indicators for identifying patients who are approaching the end of their life and in need of palliative care.

Identified as approaching end of life

	Grade
g the end of life in a timely way and have the capability to record identification.	A
e right time to receive care and support to meet their needs and preferences.	A
fy people approaching the end of life in a timely way.	A
approaching the end of life in a timely way.	A
e of their tendency to overestimate survival, as it may affect patients' prospects	B
f people approaching the end of life.	B
g the end of life.	B
e palliative care register	C
nt were to die in the next year/months/weeks?". If it would not be a surprise,	C
ce of predicting patients approaching the end of life , e.g. the revised	B
Palliative Care Needs (RADPAC) to identify patients with CHF, COPD, or cancer	B

Intervention	
Prognostic indicators for assisting clinicians	
Encourage:	
2.2.13	health professionals to review prognostic indicators of their patients with advanced age; malnutrition; comorbid illness; increasing organ dysfunction; and frailty, to identify patients who are approaching the last year of their life.
2.2.14	health professionals to review prognostic indicators of their patients with heart failure and chronic obstructive pulmonary disorder, in order to identify those at high risk of death.
2.2.15	clinicians to use Clinical Prediction of Survival (CPS) in combination with other prognostic predictions.
2.2.16	health professionals to review prognostic indicators of their patients with cancer, including performance predictors in advanced cancer. The Karnofsky Performance Status (KPS) is a widely used performance predictor with good reliability and validity.
2.2.17	health professionals to include the additional prognostic value of frailty and other factors, to improve estimation of survival probabilities for patients with advanced cancer.
Identifying people approaching end of life	
Encourage:	
	health professionals to review prognostic indicators to identify those at high risk of death.
2.2.18	congestive heart failure
2.2.19	chronic obstructive pulmonary disease
2.2.20	dementia
2.2.21	geriatric failure to thrive
2.2.22	hepatic disease
2.2.23	renal disease
2.2.24	geriatric patients in care homes who are failing to thrive.

	Grade
Patients with non-cancer long term conditions, including poor performance status; respiratory dysfunction; hospitalisation for acute decompensation, in order to identify those	B
Patients with non-cancer long term conditions especially dementia, congestive heart failure to identify those who are approaching the last year of their life.	B
Combining with other prognostic factors or scores to improve the accuracy of their	A
Patients with cancer. Performance status is one of the most significant survival predictors in the Karnofsky Performance Scale (KPS) and the Eastern Cooperative Oncology Group (ECOG) scales, both have	B
Health-related quality of life data to that of socio-demographic and clinical data in patients with cancer.	A
Use patients with a median survival of 6 months or less for:	
	B
	B
	B
	B
	B
	B
	C

2.3 Recommendations for interventions to increase the number of people identified

This evidence review recommends:

Intervention	
Commissioners and service providers	
Ensure:	
2.3.1	once people have been identified as approaching the end of life, the
2.3.4	people approaching the end of life have the opportunity to discuss and review a care plan detailing their preferences for current and future
2.3.5	comprehensive holistic assessments for advance care planning are conducted by health professionals, as well as other appropriate support services.
2.3.6	assessments encompass all aspects of end of life care, taking into account the needs of the patient, family and carers.
2.3.8	patients' individual needs are assessed.
2.3.9	patients do not receive unnecessary repeated assessments from different
2.3.2	systems are in place to enable comprehensive holistic assessment and
2.3.3	response to their changing needs and preferences, with the opportunity for future support and treatment.
2.3.7	provider organisations employ health and social care professionals
Structured assessments	
Ensure:	
2.3.10	structured assessments are undertaken at key points in the patient's journey among the multidisciplinary team. Findings should be discussed and
2.3.11	the structured assessment is an on-going process that is updated regularly
2.3.12	all patients with advanced cancer have their physical, psychological and social aspects of care assessed on a regular basis.
2.3.13	assessments are made by health care professionals who have received

Identified as approaching end of life with advanced care plans

	Grade
They receive a prompt initial holistic assessment.	A
their needs and preferences. This includes the opportunity to develop and the support and treatment.	A
be multidisciplinary and have input from both health and social care	A
account the preferences of the person approaching the end of life, and their	A
	A
different professionals aiming to elicit similar information.	A
s to be carried out with people identified as approaching the end of life, in community to discuss, develop and review a personalised care plan for current and	A
s that have received training in assessing patients' and carers' needs.	A
t pathway with locally agreed format and mechanisms for sharing the data t multidisciplinary team meetings.	A
throughout the course of a patient's illness.	A
, social and spiritual needs, and their preferences for the nature and location	A
ived further education and training in palliative care	A

Intervention	
Advanced care plans	
Promote:	
2.3.14	key components of best practice in supporting community palliative care include: <ul style="list-style-type: none"> • agreed identification criteria and a management plan discussed with patients and their carers are regularly assessed using agreed criteria; • anticipated needs are noted, planned for and addressed; • patient and carer needs are communicated within the team; • preferred place of care and place of death are discussed and agreed; • co-ordination of care is orchestrated by a named person in a named role; • relevant information is passed to those providing care out of hours; • a protocol for care in the dying phase is followed, such as the Dying Pathway for the last two days of life; • carers are educated, enabled and supported, which includes access to education, training, support groups, peer support, supervision, audit, reflective practice, development of practice protocols and provider organisation development plans.
2.3.31	simple patient-directed educational interventions to support the completion rate of advance directives
2.3.32	direct counselling to support the completion rate of advance directives
2.3.33	clinician-initiated discussion to support the completion rate of an advance directive
2.3.34	direct patient–healthcare professional interactions over multiple visits
2.3.35	combined written and verbal educational interventions to support the completion rate of advance directives
2.3.36	a combination of informative material and repeated conversations to support the completion rate of advance directives
2.3.37	interactive informative interventions to support the completion rate of advance directives
2.3.38	multiple sessions of direct interaction between patients and healthcare professionals to support the completion rate of advance directives
2.3.39	interaction with a knowledgeable person to support the completion rate of advance directives

	Grade
<p>end of life care advanced care planning, including:</p> <ul style="list-style-type: none"> discussed within the multidisciplinary team; standardised assessment tools; shared with primary care and to specialist colleagues, as appropriate; documented and noted, and measures taken to comply, where possible; available to a General Practice team; documented hours, and anticipated prescribed drugs left in the home; aligned with the Liverpool Care Pathway for the Dying Patient or the Welsh Integrated Care Pathway. 	A
<p>provision of specific information, financial advice and bereavement care;</p> <p>and targeted learning are encouraged as part of personal, practice and organisational learning.</p>	
<p>completion rate of advance directives.</p>	B
<p>completion rate of advance directives.</p>	B
<p>completion rate of advance directives.</p>	B
<p>clinical visits to support the completion rate of advance directives.</p>	B
<p>completion rate of advance directives in clinic outpatients and hospitalised elderly.</p>	A
<p>completion rate of advance directives over clinical visits to support the completion rate of advance directives.</p>	A
<p>completion rate of advance directives.</p>	B
<p>completion rate of advance directives in primary care professionals to support the completion rate of advance directives.</p>	B
<p>completion rate of advance directives.</p>	B

Intervention	
2.3.40	the availability of a person who can answer questions and assist with directives.
2.3.41	communications where participants had the opportunity to ask questions to support completion rates.
2.3.42	opportunities for group interaction to intensify the discussion and directives.
2.3.43	interventions that include repeated contacts or stimuli toward advance care planning.
2.3.44	two or more home care visits by the community health nurse to improve completion rates.
2.3.14	key components of best practice in supporting community palliative care.
Advanced care planning communication	
Ensure:	
2.3.15	communication about prognosis is included as an essential aspect of advanced care planning.
2.3.17	caregivers of palliative patients have information and support needed to provide care.
2.3.19	information is provided using plain language and the patient's understood level of cognitive function.
Promote:	
2.3.16	discussion about prognosis and advance care planning within one or more visits.
2.3.18	advanced care planning communication strategies that include the following: <ul style="list-style-type: none"> • facilitate the establishment of a close rapport with the patient; • identify the patient's information preferences; • ensure comprehension of key knowledge and information; • address the patient's emotions in a supportive fashion; • elicit the patient's key concerns • involve the patient in the treatment plan.
2.3.20	provision of information verbally regarding advanced directives over the phone.

	Grade
with advance directive completion to support the completion rate of advance	B
questions and/or receive assistance completing advanced directive forms to	B
question and answer process to support the completion rate of advance	B
advance directive completion.	B
improve completion rates of advance directives.	B
advance care advance care planning.	A
of effective advance care planning and that it is documented effectively.	B
needs is met, especially prognostic and disease-related information needs.	B
understanding of the information that has been conveyed is checked.	B
month of a patient's new diagnosis of advanced cancer	B
the following:	B
over multiple sessions.	A

Intervention	
Sentinel events	
2.3.21	Ensure there are minimal standards for when advance care planning is carried out before an expected death from cancer, and other sentinel events.
Health professional communications	
Promote:	
2.3.22	patient-physician communication techniques to improve the frequency of
2.3.23	educational interventions for physicians to increase the ability of physicians to
2.3.24	palliative care/coordinated care intervention to improve completion of
2.3.25	oncologists being encouraged to be open with patients about prognosis and end-of-life care in the context of their patient's disease.
2.3.26	multi-component social work-based intervention that includes communication assessment, and advance care planning improved documentation
Involvement of palliative care team	
2.3.27	Promote the inclusion of a palliative care team as part of the multi-disciplinary team until severe symptoms emerge may aid in the adjustment process. Consider patient preferences.
Identification of people with cognitive impairment	
Promote:	
2.3.28	advance care planning to reduce inappropriate hospital admission
2.3.30	advance care planning being carried out before mental capacity is lost, and patient preferences for care, so that if, in future, they cannot make decisions
2.3.29	Ensure advance care planning is carried out in the earlier stages of illness to support best interest decision-making.

	Grade
ng should be discussed in cancer patients including at diagnosis of cancer,	B
ency of advance directive completion.	B
hysicians to elicit patient preferences.	B
n of advance directives for patients.	B
agnosis and be comfortable addressing sensitive issues such as future goals of	B
nselling by social workers specifically trained in communication skills, capacity of patients' wishes regarding common life-sustaining treatments.	B
disciplinary team early after the diagnosis of cancer as opposed to waiting. However, ultimately the timing should be guided by each individual's	B
s and health-care costs for people with cognitive impairment and dementia.	B
lost. Advance care planning allows a patient to discuss and write down their ns their wishes are known.	C
f the illness before capacity is lost, after which seek proxy views to facilitate	C

Intervention	
Transfer interventions	
Promote:	
2.3.48	a standardised patient transfer form to assist with the communication
2.3.49	pharmacist-led review of medication lists to identify omitted or incorrect

This evidence review does not recommend:

Intervention	
2.3.50	Passive education of patients using written materials (without direct
2.3.52	Education without the ability to ask questions.
2.3.53	Didactic interventions.
2.3.54	The addition of video instruction when compared to the effectiveness

	Grade
tion of advance directives and medication lists.	B
icated medications on transfer of medication lists and advance directives.	B

	Grade
ct counselling) in the primary care setting.	B
	B
	B
ess of written materials.	B

2.4 Recommendations for interventions to promote the number of people c

This evidence review recommends:

Intervention	
Integrated care pathways	
2.4.1	People approaching the end of life should receive care that is aligned with their preferences (including where care is spent in preferred place of care during the last year of life).
2.4.2	People approaching the end of life should have a reduction in unnecessary hospital care (including where care is spent in hospital is against their stated preference).
2.4.4	Promoting an integrated approach to provision of services is fundamental to ensuring high quality care for people approaching the end of life and their families and carers.
Ensure:	
2.4.3	services are commissioned from and coordinated across all relevant organisations to ensure a seamless end-of-life care pathway.
2.4.5	people approaching the end of life receive consistent care that is available 24 hours a day or night, and delivered by practitioners who are aware of the needs and preferences of the individual.
2.4.6	people approaching the end of life who experience a crisis at any time of day or night receive care that is responsive to their needs and preferences.
2.4.7	people approaching the end of life who may benefit from specialist services receive care that is responsive to their needs and preferences, at any time of day or night.
2.4.8	social care workers have the knowledge, skills and attitudes necessary to provide care for people approaching the end of life and their families and carers.
2.4.9	generalist and specialist services providing care for people approaching the end of life have a workforce sufficient in number and skill mix to provide high-quality care.
Training and support of health professionals	
2.4.10	Promote training for health professionals to ensure they are equipped to provide high-quality care.

Dying in their preferred place of care and reduce the number dying in hospital

	Grade
igned to their needs and preferences that include an increased length of time	B
cheduled care hospital admissions leading to death in hospital (where death	B
amental to the delivery of high-quality care to people approaching the end of	B
ant agencies, including specialist palliative care, and encompass the whole	B
coordinated effectively across all relevant settings and services at any time of person's current medical condition, care plan and preferences.	B
time of day or night receive prompt, safe and effective urgent care appropriate	B
st palliative care, are offered this care in a timely way appropriate to their	B
ecessary to be competent to provide high-quality care and support for people	B
aching the end of life and their families and carers have a multidisciplinary ity care and support.	B
owered, enabled and supported to achieve the delivery of effective end of life	B

Intervention	
Responsive interventions	
Ensure:	
2.4.11	responsive mechanisms are implemented within each locality to advanced cancer on a 24-hour, seven days a week basis, and that medical and nursing services should have access to specialist advice.
2.4.12	primary care teams institute mechanisms to assess needs of patients, the team and with other professionals as appropriate.
2.4.14	an appropriate range and volume of specialist palliative care services. These services should, as a minimum, include specialist palliative care advice.
2.4.15	specialist palliative care advice is available on a 24 hour, seven days a week basis to patients in their own homes, community hospitals and care homes.
2.4.16	each multidisciplinary team or service implements processes for working with other service providers with whom the patient has contact. M
2.4.18	patients and carers have easy access to a range of high quality inpatient services should be free at the point of delivery and patients should be offered care in their own homes where appropriate.
2.4.19	explicit partnership arrangements are agreed between local health services and patients with cancer and their carers are met in a timely fashion in their own homes or other locations.
2.4.21	provider organisations identify staff who may benefit from training and development. Individual practitioners should ensure they have the necessary skills to provide high quality care.
Promote:	
2.4.13	access to, and availability of, specialist palliative care services.
2.4.17	responsive mechanisms to ensure the views of patients and carers are taken into account in the development of care services.
2.4.20	the nomination of a lead person to oversee the development and implementation of care services during the patient's life and in bereavement, and which reflects the views of patients and carers.

	Grade
ensure that medical and nursing services are available for patients with specialist equipment can be provided without undue delay. Those providing generalist services at all times.	B
patients with advanced cancer, and that the information is communicated within	B
services to meet the needs of the local population, based on local calculations. Services are provided in in-patient facilities and hospital and community teams.	B
on a weekly basis. Community teams should be able to provide support to patients.	B
effective inter-professional communication within teams and between them. Mechanisms should be developed to promote continuity of care.	B
Information materials about cancer and cancer services. These materials should offer appropriate help to understand them within the context of their own	B
with health and social care services and the voluntary sector to ensure that the needs of patients and that different components of social support are accessible from all	B
staff and should facilitate their participation in training and on-going education to gain the knowledge and skills required for the roles they undertake.	B
	B
Views of patients and families are taken into account in developing and evaluating cancer and palliative	B
the implementation of services that specifically focus on the needs of families and carers, and reflect cultural sensitivities.	B

Intervention	
End of life home care	
Promote:	
2.4.22	end of life home care to enable more people to die at home compared to hospital
2.4.23	support by district nurses to offer additional help to care givers living at home
Factors linked to people dying in their home	
Promote:	
2.4.24	actions to enable people to die at home: empowerment of families and training of practitioners in palliative care.
2.4.25	social support, healthcare inputs, from services and programs and family
Rural interventions	
Ensure:	
2.4.26	rural end-of-life services are integrated into rural hospitals and community health centres
2.4.27	family caregivers from rural areas are provided with more information and support
2.4.29	people living in rural areas have access to specialised palliative care services
2.4.28	promote continuing education and for improved support of rural health workers
Nurse led follow-up interventions	
Promote:	
2.4.30	nurse-led follow-up; patient-initiated or telephone follow-up coupled with home visits
2.4.31	nurse-led follow-up actions to support patients with cancer that include providing information; provision of sufficient time and encouragement for patients to ask questions; tests and examinations not to be conducted purely for reassurance; ensuring that patients have the information needed and informed choice for patients about attendance for services

	Grade
pared with those receiving usual care.	A
ooking after the patients especially with night nursing.	B
es, public education, home based models of care, assessment of risk, and	B
nd healthcare provider contact, and patient preferences.	B
ll other health care organisations.	B
tion and support, particularly in the form of home-based nursing care.	B
are and home care.	B
care providers.	B
nd be practical alternatives to conventional care.	B
clude: an initial care plan; provision of adequate patient education and patients to raise questions and concerns; provision of psychological support; ce; provision of contact details of a key person whom patients can contact when heduled appointments or only attending when problems or symptoms arise.	B

Intervention	
Hospice care delivered at home	
Promote:	
2.4.32	hospice care delivered at home, in nursing homes and in dedicated hospice services to ensure increased likelihood of effective pain management.
2.4.33	hospice services to ensure increased likelihood of effective pain management.
Supporting carers	
Promote:	
2.4.34	support for informal carers as they are central to the achievement of patient goals.
2.4.39	access to professional advice to increase carers' confidence in the care provided.
2.4.40	nurses and other health providers to assist home-based carers by providing education and training to support home-based care.
Ensure informal carers:	
2.4.37	have access to practically focused information from health professionals.
2.4.38	are offered opportunities to learn about practical nursing skills.
Ensure informal carers receive information about:	
2.4.41	<ul style="list-style-type: none"> • medication and pain management
2.4.42	<ul style="list-style-type: none"> • physical symptoms and comfort, including management of constipation and skin care; symptom recognition and prevention of delirium
2.4.44	<ul style="list-style-type: none"> • personal hygiene and elimination - bathing, cutting toenails, catheter care
2.4.45	<ul style="list-style-type: none"> • positioning - patient ambulation, lifting and handling, safe transfers
2.4.46	<ul style="list-style-type: none"> • awareness of, availability, access, optimal positioning and use of equipment
2.4.47	<ul style="list-style-type: none"> • local support - access to night services or 24-hour support
2.4.48	<ul style="list-style-type: none"> • emergency measures recognising signs of imminent death
2.4.35	Ensure older carers' needs are addressed.

	Grade
ed hospice facilities.	B
management and of death not occurring in hospital.	B
t of end of life care and death at home.	B
eir ability to undertake practical aspects of home-based care.	B
y providing them with information and skills-training necessary to facilitate	B
sionals.	B
	B
	B
t of weakness and fatigue, nausea and vomiting, mouth ulcers, oedema; wound ehydration	B
nails and dressing; bowel management; coping with incontinence; changing a	B
orting pillows	B
nd use of technical equipment	B
ort; signposting to local resources and/or agency help	B
th; knowledge of emergency measures and provision of emergency contacts	B
	B

2.5 Recommendations for interventions to promote end of life care staff training

This evidence review recommends:

Intervention	
Provider	
2.5.1	All health and social care professionals receive training in assessing and ensure they have received such training before undertaking assessments.
2.5.2	Promote communication skills training programmes on the introduction of end of life care.
Curricular interventions	
Promote:	
2.5.3	a palliative care curriculum with a multifaceted approach, incorporating simulation where required.
2.5.4	communication skills in palliative care utilising simulated patients in training.
2.5.5	a modular approach to End of Life education.
2.5.6	a multifaceted approach with focus on individual competencies to meet the needs of end of life care.
Intensive care unit staff training	
2.5.9	Promote increased collaboration and communication between health professionals to improve physician/nurse satisfaction.
Ensure:	
2.5.7	critical care physicians are competent in family-centred End of Life care.
2.5.8	all intensive care unit professionals receive adequate support and training.
2.5.10	there is sufficient time and space made available for professional continuing education, seminars, and inter-professional dialogues can increase understanding.
2.5.11	nurses' role in end-of-life decision making is valued and included.

ing

	Grade
patients' and carers' needs. These professionals have a responsibility to	A
ents.	
tion of palliative care.	A
ing a variety of intentional strategies to address the multiple competencies	B
n a short 2-hour session or a full-day workshop.	B
	B
meet all of educational requirements of postgraduate learners in end-of-life	B
h professionals in order to achieve more appropriate care and increased	B
ommunication.	B
ppropriate end-of-life education.	B
versations and reflection about care, use of joint grand rounds, patient care	B
ing and desire to have interdisciplinary end-of-life care.	
	B

Intervention	
Palliative care nurse training	
Promote:	
2.5.12	transfer of communication skills training to practice by clinical super
2.5.13	a combination of communication skills training and managing death
2.5.14	palliative care courses that address general care and mental health
2.5.15	a mixture of didactical methods and a combination of multiple them integrated with practical experiences.
Medical undergraduate training	
2.5.17	development of more academic departments of palliative care would
2.5.19	use of small groups for problem based learning.
Promote:	
2.5.20	inclusion of multidisciplinary teaching.
2.5.21	involvement of all team members along with the patient and family i
2.5.22	integration of teaching and combination of disciplines and principles
2.5.23	fostering of reflective learning.
2.5.24	inclusion of ethical and legal issues of relevance to end of life care.
Ensure:	
2.5.18	knowledge and essential core information is taught.
2.5.25	students acquire effective mechanisms to deal with the professional
Specific oncology training	
Promote:	
2.5.26	specialist training for oncologists. Physicians can be trained to meet developed concise communications skills training called COM-ON-p.
2.5.27	COM-ON-p communication skills training. A COM-ON-p communicati practical, relevant, and of high personal benefit.

	Grade
vision.	C
education to improve skills outcomes.	C
care as well.	C
es delivered over a period of several weeks. As well as ensuring the training is	B
l facilitate palliative care teaching.	B
	B
	B
n the teaching.	B
s throughout the curriculum.	B
	B
	B
	B
and personal pressures of this aspect of their work.	B
better core challenges during the transition to palliative care through	B
on skill training has been well accepted; oncologists rated COM-ON-p as highly	B

Intervention	
E-learning interventions	
Promote:	
2.5.28	palliative care education using e-learning platforms.
2.5.29	E-mailed fast facts and concepts as an educational intervention that symptom management skills.
Communications skills training	
Promote:	
2.5.30	three day communication skills courses to train nurses in end of life
2.5.32	nurses' communication skills training, to improve patient satisfaction

This evidence review does not recommend:

Intervention	
2.5.33	E-mailed fast facts and communication skills or learner satisfaction

2.6 Recommendations for interventions to support people who are bereaved

This evidence review recommends:

Intervention	
Models of bereavement support	
2.6.1	2004 NICE guidance recommends that a three-component model of bereavement support be offered to people who are bereaved. The Cancer Network to ensure that people's individual needs are addressed. This model takes account of the standards for bereavement care developed by the NICE and is accessible when needed around the time of bereavement.
	Component 1: Grief is normal after bereavement and most people do not require professional support. However, some people may require professional support. Offered information about the experience of bereavement and how to access support.
	Component 2: Some people may require a more formal opportunity to talk to a professional. Some people may have to involve professionals. Volunteer bereavement support workers provide much of the support at this level.

	Grade
	B
increases intern medical knowledge and self-reported preparedness in	B
care.	B
on with nurses' communication.	B

	Grade
with palliative care concepts assists in preparedness in education.	B

ed

	Grade
of bereavement support should be developed and implemented in each essed through variety in service provision. Cancer Networks should take ational Bereavement Consortium. The components should be flexible and	A
manage without professional intervention. All bereaved people should be y to access other forms of support.	
y to review and reflect on their loss experience, but this does not necessarily kers/befrienders, self-help groups, faith groups and community groups will	

Intervention	
	Component 3: A minority of people will require specialist intervent specialist counselling/psychotherapy services, specialist palliative for meeting the specialist needs of bereaved children and young p
Commissioners	
2.6.2	Commission services for people closely affected by a death that in bereavement, emotional and spiritual support appropriate to their
2.6.3	Commissioners, working through Cancer Networks, should ensure arrangements) and bereavement services are in place to meet the and social care agencies to achieve this. While not necessarily sep fully integrated), commissioners should ensure sufficient capacity
Provider	
2.6.4	Service providers should ensure that systems are in place for peo provision for immediate and ongoing bereavement, emotional and
2.6.5	Ensure families and carers have access to professionals capable o the needs, choices and judgements of a family member or carer an offered to the patient.
2.6.6	Providers of specialist bereavement support should work closely w family members can access services when needed.
2.6.7	Ensure a nominated lead to oversee the development and implem
2.6.8	Organisations should be equipped to offer the first component of f components. Services should be accessible from all settings.
2.6.9	Provide an information leaflet including information on anticipated to families and carers around the time of the bereavement. Ideally of bereavement services.
2.6.10	Providers should ensure all staff working with people who are dyin the difference between personal and professional responses to los one-to-one and group support.

	Grade
ions. This will involve mental health services, psychological support services, e care services and general bereavement services, and will include provision eople.	
clude sensitive communication and provision for immediate and ongoing r needs and preferences.	A
that a range of information, support (including practical help and respite spectrum of need. They will need to work with statutory and voluntary health arate from many of the services provided to patients (indeed, most will be to meet the distinct needs of this group.	A
le closely affected by a death that include sensitive communication and l spiritual support appropriate to their needs and preferences.	A
f providing confidential emotional support and, if there is variance between d those of the patient, the professional is independent of normal services	A
with other care providers (both statutory and voluntary) to ensure carers and	A
entation of services that specifically focus on the needs of families and carers.	A
ereavement support and have strategies in place to access the other	A
d feelings and how to access local and national services and made available, this should be developed locally, agreed by those involved in the provision	A
g have access to a range of opportunities to address concerns and explore ss. This might involve a number of processes, such as clinical supervision and	A

Intervention	
Health and social care workers	
2.6.11	Health and social care workers should communicate sensitively with bereaved families, providing bereavement, emotional and spiritual support appropriate to their needs.
2.6.12	Health and social care professionals involved in providing day-to-day care should offer bereavement support to patients and carers on an ongoing basis. Teams should establish a system for identifying and addressing particular concerns.
2.6.13	Health and social care professionals involved in delivering care in the home should assess patients' ability, stress levels, available support and actual and potential needs.
2.6.14	Teams should ensure that all family members and carers are offered bereavement support. Health professionals should provide more detailed accounts of cancer, its treatment and prognosis. Local and national sources of information, advice and practical support for carers and families should be listed in the directories developed by the Cancer Network.
Specialist bereavement services	
2.6.16	Specialist bereavement services should be sufficiently resourced to meet the needs of bereaved families and social care professionals in relation to this aspect of care.
2.6.17	Those who offer bereavement services that include volunteer support should ensure that training and managing volunteers are in place. It is desirable that the work is supported by a dedicated service.
Cancer Network	
2.6.18	Cancer Network-wide protocols should be developed to inform the delivery of bereavement support, specialist referral, particularly for those at risk of complicated grief.
2.6.19	Ensure all health care professionals involved in the delivery of support are aware of bereavement support, understanding and meeting the needs of families and carers.
Family and carers	
Ensure:	
2.6.21	that all bereaved families and carers are communicated with in a sensitive and timely manner and provided with emotional and spiritual support appropriate to their needs and preferences.

	Grade
Health professionals should assess the needs of people closely affected by a death and offer them immediate and ongoing bereavement support in line with their needs and preferences.	A
Health professionals providing palliative care to patients should assess and address the needs of family members to ensure family members and carers have regular opportunities to discuss their concerns.	A
Health professionals in the terminal phase of illness should assess individual and family coping strategies and bereavement needs with respect to the anticipated or actual bereavement.	A
Health professionals should provide bereavement information on a variety of topics, from a simple 'who's who' of local support groups to more detailed information on consequences and services available locally. They should be 'signposted' to local bereavement support, including sources of emotional and psychological support. Services should be available at Cancer Network level.	A
Health professionals should ensure that bereavement support is available to enable them to contribute to the preparation and ongoing support of health professionals.	A
Health professionals should ensure that bereavement support workers should ensure mechanisms for recruiting, training, supervising and supporting bereavement support workers whose workforce reflects the gender, age distribution and ethnicity of the clients they support.	A
Health professionals should ensure that bereavement support is available at a level of bereavement support offered and the need for follow up and support for bereavement reactions.	A
Health professionals providing palliative and hospice care services have access to basic training in bereavement support.	A
Health professionals should ensure that bereavement support is offered in a sensitive way and are offered immediate and ongoing bereavement, emotional and practical support.	A

Intervention	
2.6.22	families and carers of people who have died suddenly or in an unexpected death receive information and support appropriate to their circumstances.
2.6.23	people closely affected by a death have access to support within a reasonable time.
2.6.24	family members and carers are offered the opportunity for their needs to be met by patients. Cultural and ethnic preferences on family involvement should be considered.
2.6.25	family members and carers are invited to accompany patients during their final care, in accordance with the patient's wishes.
2.6.26	family members and carers are made aware of, and have easy access to, bereavement support services to meet their own needs.
2.6.27	family members and carers who are bereaved are, in the first instance, offered support. If support is insufficient, or it is predicted that those involved are likely to experience significant distress, further support is offered.
2.6.28	where carers are providing a substantial amount of care on a regular basis, bereavement support is offered to the carer as well as the bereaved family member.
Ongoing support	
2.6.29	Ensure bereavement support is not limited to immediately after death. Support should be available for a period of time, and, in some cases bereavement support may begin before death.
Information	
2.6.30	Promote a stepped approach to emotional and bereavement support services, including: <ul style="list-style-type: none"> • information about local support services • practical support such as advice on arranging a funeral, information on what to do with equipment and clothing, and information on what to do with the body • general emotional and bereavement support, such as support groups, from the voluntary, community sectors • referral to more specialist support from trained bereavement counsellors

	Grade
expected way, as well as those who were expecting the death, have access to	A
an appropriate physical environment that facilitates sensitive communication.	A
needs for support and information to be assessed separately from those of should be taken into account.	A
ing clinical encounters and are involved in discussions about treatment and	A
ess to, sources of local information, advice and support designed to meet their	A
ance encouraged to use existing support systems. Where these prove experience difficult grief reactions, there should be access to additional help and	A
ar basis, providers offer a separate assessment or respond positively when a	A
death, but that there is provision for it to be available on a longer-term basis	A
ort, which could include but is not limited to:	A
ormation on who to inform of a death, help with contacting other family and medication	
ortive conversations with generalist health and social care workers or support	
at counsellors or mental health workers.	

Intervention	
2.6.31	Ensure relatives of patients who are dying in the ICU are provided with a strategy that includes longer conferences and more time for family.
2.6.32	Ensure people closely affected by a death have access to all support and communication.
Cultural and spiritual interventions	
Ensure:	
2.6.33	bereaved people are offered support at the time of death that is culturally appropriate afterwards.
2.6.34	ensure awareness of the needs of different ethnic populations, including ensuring teams have access to reference guides on the cultural differences and information on accessing interpreters, relevant health advocates (youth workers).
Children and teenager interventions	
2.6.35	Ensure patients with young children or teenagers are offered information on how to encourage the sharing of fears and concerns. Age-appropriate support should be provided.
Promote:	
2.6.36	support groups for family members and carers, either professional or peer support, in difficult situations. These services are ideally provided in partnership with bereavement services.
2.6.37	family bereavement programmes to reduce mental health problems.
Complex support interventions to support complicated grief	
2.6.38	Ensure there is provision for family members and carers who will require support of dealing with complex family situations. Providers should ensure staff have the knowledge to offer social support, spiritual support, specialist palliative care. Agreements should be agreed between different services.
2.6.39	Promote treatment interventions that effectively diminish complicated grief.
Carers who are close to being bereaved	

	Grade
with a brochure on bereavement and using a proactive communication members to talk may lessen the burden of bereavement.	B
ort within an appropriate physical environment that facilitates sensitive	A
culturally and spiritually appropriate, immediate, and available shortly	A
differences in language, religious practice and culture. Providers should differences surrounding a diagnosis of cancer, death and dying, and that (where available) and faith leaders is readily accessible.	A
mation by health and social care professionals providing day-to-day care on late resources should be available to support this process.	A
ly or peer-led, to meet other families and carers who have experienced similar the voluntary sector.	A
s of bereaved youths and their parents.	B
require care and support from a health or social care professional capable they have access to individuals and teams with the requisite skills and liative care or psychological support services. Criteria and routes for referral	A
ated grief symptoms.	B

Intervention

2.6.41	Ensure that teams have the ability to offer information and training or help with activities of daily living or approaching the terminal stage of symptoms and dealing with incontinence and other body fluids. As de
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Neo-natal and peri-natal support to parents

Promote:

2.6.42	support to families and facilitation of emotional adjustment following
2.6.43	support to families and facilitation of emotional adjustment following
2.6.44	Ensure hospital nurses, and doctors support perinatal loss sensitivel postpartum care, encourage parental contact with the deceased infan

Carers of people with dementia

2.6.45	Ensure there is adequate support for carers of people with dementia.
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Promote:

2.6.46	pre-loss interventions to support Alzheimer’s care-givers’ post-loss a individual depending on the initial clinical presentation.
2.6.47	Resources for Enhancing Alzheimer’s Care-giver Health (REACH) Progra

Primary care staff interventions

2.6.48	Ensure GPs and district nurses receive adequate end-of-life training.
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Psychotherapeutic support

2.6.49	Consider promoting psychotherapeutic interventions for bereaved per adapting to loss.
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Parenting interventions

2.6.50	Consider promoting a family bereavement programme on effective pa
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This evidence review does not recommend:

Intervention

2.6.51	Preventive interventions for diminishing complicated grief symptoms
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	Grade
on practical issues to carers who are looking after patients requiring extra care at the end of illness. This might include manual handling, managing distressing symptoms, and death approaches, they should also be given information about what to expect.	A
g the death of a child.	B
g the death of a baby.	B
y and increase parental choice about timing and location of delivery and care, and facilitate provision of photos and memorabilia.	B
	B
adjustment following the death of their care recipient, tailored to the needs of the bereaved.	B
amme for Bereaved Care-givers .	B
	C
ersons that are exclusively targeted at grievors displaying marked difficulties	B
renting.	B
	Grade
	B

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