


## SOMERSET END OF LIFE CARE STRATEGY

**2016-2019**

Adopted by

	Somerset Partnership NHS Foundation Trust
	Yeovil District Hospital NHS Foundation Trust
	Taunton & Somerset NHS Foundation Trust
	St Margaret's Hospice
	Dorothy House Hospice care
	Weston Hospice Care

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# SOMERSET CLINICAL COMMISSIONING GROUP

## END OF LIFE CARE STRATEGY

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## END OF LIFE CARE STRATEGY

### VERSION CONTROL

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1.0	18 Dec 2015	Initial draft
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<b>Sponsoring Director:</b>		Lucy Watson
<b>Author(s):</b>		Director of Quality Safety and Governance
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## EQUALITY IMPACT ASSESSMENT FORM

### INITIAL INFORMATION

Name of policy/service: End of Life Care Strategy Version number (if relevant):	Directorate/Service: Quality, Safety and Governance
Assessor's Name and Job Title: Wendy Green, End of Life Care Practice Educator  Telephone: 01935 384194 / 07500784903	24 Feb 2016
Sponsoring Director: Lucy Watson Director of Quality Safety and Governance	Date: 22 August 2016

Please refer to the Equality Impact Assessment Guidance to complete this form.

<b>OUTCOMES</b>
Briefly describe the aim of the policy / service and state the intended outcomes for patients and/or staff?
<p>This is an update of the Somerset End of Life Care Strategy 2008, building on the Somerset Delivering Choice Programme, which ran from 2008 until 2012. It sets out the local vision for end of life care which is personalised, well-coordinated and enables choice for patients.</p> <p>It aims to ensure that all patients at end of life, together with those closest to them, are able to express their needs and wishes, and that as far as clinically appropriate and practically possible, these needs and wishes are met.</p> <p>These aims will be met through commissioning integrated health and social care for end of life care services which embed best practice, via collaborative working amongst all providers contributing to care in Somerset.</p>
<b>EVIDENCE</b>
What data / information have you used to assess how this policy / service might impact on protected groups?
Progress against the 2008 End of Life Care Strategy and quality and effectiveness of the services provided has been monitored by the Palliative Care and End of Life

Clinical Programme Group. This oversight includes periodic review of patient complaints and also opportunities to share and learn from individual patient stories. The End of Life Care Coordination Centre also periodically provide anecdotal evidence about patients with specific needs such as older people, children and young people, people with disabilities and how their care needs have been accommodated and met.

Data has been collected on the place of death for the population of Somerset for the years 2009 - 2015.

One Chance to Get it Right' Report (June 2014) – published by the Leadership Alliance for the Care of Dying People (LACDP), which was established following an independent review of the Liverpool Care Pathway for the Dying Patient (LCP)

The National Palliative and End of Life Care Partnership, Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020

Every Moment Counts', the narrative for 'person-centred coordinated care' produced for NHS England by National Voices in 2014

Deprivation and death: Variation in place and cause of death - National End of Life Care intelligence network (2012)

Who have you consulted with to assess possible impact on protected groups?  
If you have not consulted other people, please explain why?

This Equality Impact Assessment was discussed and agreed with the CCG's Equality, Diversity and Patient Engagement Lead.

## ANALYSIS OF IMPACT ON EQUALITY

The Public Sector Equality Duty requires us to eliminate discrimination, advance equality of opportunity and foster good relations with protected groups. Consider how this policy / service will achieve these aims.

Please read 'Questions to Ask' in the EIA guidance.

Note: in some cases it is legal to treat people differently (objective justification).<sup>1</sup>

- *Positive outcome – the policy/service eliminates discrimination, advances equality of opportunity and fosters good relations with protected groups*
- *Negative outcome – protected group(s) could be disadvantaged or discriminated against*
- *Neutral outcome – there is no effect currently on protected groups*

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<sup>1</sup> See definition of 'objective justification' in guidance

Please tick to show if outcome is likely to be positive, negative or neutral.  
Consider direct and indirect discrimination, harassment and victimisation.

Protected Group	Positive outcome	Negative outcome	Neutral outcome	Reason(s) for outcome
Age	✓			Significant proportion of patients affected by this policy will be over 65 years old
Disability <sup>2</sup>	✓			Significant proportion of patients affected by this policy will have a physical disability
Religion and belief	✓			Patients' beliefs and wishes are respected at end of life, having discussed and agreed what matters to them as part of Advanced Care Planning discussions
Sex			✓	End of life care is provided to all people regardless of gender
Sexual Orientation			✓	Consideration of sexual orientation and involvement of partners will be addressed by individual Provider Organisations through their end of life care plans with individuals
Gender Reassignment			✓	Consideration of gender reassignment and additional sensitivity at end of life will be addressed by individual Provider Organisations through their end of life care plans with individuals
Race			✓	End of life care is provided to all people regardless of race. Individual needs will be addressed by Provider Organisations through individual end of life care plans
Pregnancy and maternity		✓		It will be rare for pregnant women and women who have recently delivered to also be in receipt of end of life care.
If applicable, Other Disadvantaged Groups (for example carers, veterans and military staff, homeless) <sup>3</sup>	✓			Underpinning national guidance and strategies will inform individual end of life care plans and a focus on the needs and wishes of carers as well as patients

<sup>2</sup> Includes mental impairment, learning difficulty (dyslexia). Full definition in guidance.

<sup>3</sup> These groups are not protected groups under the Equality Act 2010 but should be considered alongside the protected groups where applicable.

**MONITORING OUTCOMES**

Monitoring is an ongoing process to check outcomes. It is different from a formal review which takes place at pre-agreed intervals.

What methods will you use to monitor outcomes on protected groups?

Review and monitoring of implementation of the Strategy will take place through the Palliative Care and End of Life Clinical Programme Group and through contract review meetings for commissioned services  
Reports on the expected outcomes will be provided from the Adastra End of Life Care register and by regular access to carer and family experience and review of the National Voices Survey to inform service development. We will work to ensure that there is equality and diversity information shared with the EPaccs end of life register so we can monitor impact on the nine protected groups.

**REVIEW**

How often will you review this policy / service? (Minimum every three years)

Formal review of this strategy will be undertaken at the end of its 3 year term, but ongoing review of its implementation is the responsibility of the Palliative Care and End of Life Clinical Programme Group, which meets quarterly,

If a review process is not in place, what plans do you have to establish one?

## IMPLEMENTING THE POLICY / SERVICE

### Negative outcomes – action plan

An Equality Impact Assessment cannot be signed off until negative outcomes are addressed. What actions you have taken / plan to take to remove / reduce negative outcomes?

Action taken / Action to be taken	Date	Person responsible
No negative outcomes identified		

NEGATIVE OUTCOMES cont.

If a negative outcome(s) remain explain why you think implementation is justified.

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Equality Impact Assessment forms must be authorised by the sponsoring Director

Send completed form to the Patient Experience Team at [EIA@somersetccg.nhs.uk](mailto:EIA@somersetccg.nhs.uk). This form will be published on the Somerset Clinical Commissioning Group website.

The EIA form and guidance are currently available on NHS Somerset website:

<http://www.somerset.nhs.uk/welcome/about-us/equality-and-diversity/equality-impact-assessments/>



# END OF LIFE CARE STRATEGY

2016-2019

## OVERVIEW

This Strategy has been developed by Somerset CCG's Palliative & End of Life care Clinical Programme Group and has been adopted by the following organisations

- Somerset Partnership NHS Foundation Trust;
- Yeovil District Hospital NHS Foundation Trust;
- Taunton & Somerset NHS Foundation Trust;
- St Margaret's Hospice;
- Dorothy House Hospice care;
- Weston Hospice Care.

Somerset's End of Life Care Strategy sets out the local vision for end of life care which is personalised, well-coordinated and enables choice for our patients. Our vision is that all patients at end of life, together with those closest to them, are aware of choices available to them, are empowered and able to express their needs and wishes for their care at the end of their lives, and that as far as clinically appropriate and practically possible, these needs and wishes are met. The Strategy builds on the predecessor Somerset PCT End of Life Care Strategy, which utilised the Somerset Delivering Choice Programme, which ran from 2008 until 2012, in which initiatives were introduced that include an end of life care coordination team, an out-of-hours advice and response line, support workers providing health, social and personal care, and an information website.

This strategy builds on local research including views of local patients and carers, 2015 NICE Care of dying adults in the last days of life (December 2015), NICE Quality Standards for End of Life Care, One Chance to get it Right and themes from the National End of Life Care Strategy and its Annual Reports. It details the current understanding of need and, service provision in Somerset to inform the future plans to commission integrated end of life care for all patients with active, progressive and advanced disease, irrespective of their diagnosis. It acknowledges the key role played by family members, friends and carers in supporting those approaching their end of life and thus the need to ensure that they are supported to undertake their chosen role.

In Somerset there are a range of high quality specialist and generalist end of life care services. Around 36% of deaths of people currently occur in acute hospitals and 30% in care homes. The current rate of death for people in their own home remains around 22% - national research has shown that between 50 and 70% of people would prefer to die in their own home.

Somerset CCG End of Life Care Strategy outlines a plan to realise the local vision for end of life care through commissioning integrated end of life services for health and care which embed best practice, working closely with all providers contributing to care in Somerset.

# END OF LIFE CARE STRATEGY 2016-2019

## 1. INTRODUCTION

- 1.1 Somerset End of Life Care Strategy is guided by the themes in the National End of Life Care Strategy and the local themes from patient experience and patient and carer feedback. It has been developed in partnership with providers and it updates the former Somerset PCT End of Life Care Strategy 2008 taken forward by the End of Life Care Commissioning Group.
- 1.2 The Strategy articulates the vision to commission integrated end of life care for all patients with advanced disease, irrespective of their diagnosis. It acknowledges that in many cases those approaching their end of life are living with multiple long term conditions, including chronic diseases such as diabetes, cardiac and respiratory conditions, alongside dementia and mental health conditions and cancer. The strategy is principally about care for adults, although it is recognised that work needs to be carried out on transition issues, where young people cared for by the Children's hospice reach adulthood, and may need further support.
- 1.3 This strategy compliments Somerset CCG plans for Outcome Based Commissioning. It links with the relevant programme boards including Somerset Together, Symphony Test and Learn sites, Urgent Care, Collaborative Commissioning, Community Services Programme Board, and Clinical Programme Boards.

## 2. DEFINING END OF LIFE CARE

- 2.1 End of Life Care (EOLC) can be defined as care that 'helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.' (*National Council for Palliative Care 2006*).
- 2.2 The definition of when 'end of life' begins can be a difficult concept to grasp and varies according to the perspectives of individual patients, professionals and care services. The suggested professional indicators are:
- **The surprise question:** Would you be surprised if this patient were to die in the next 12 months?;
  - **Choice:** When a patient with advanced disease makes a choice to focus on dying well supported by palliative end of life care;

- **Need:** When a patient with advanced progressive disease would benefit from a palliative care approach;
- **Clinical Indicators:** The Gold Standards Framework Prognostic Indicator Guidance, and the Supportive and Palliative Care;
- Indicators Tools are useful guides for clinicians assessing disease severity across a range of conditions.

2.3 Although the terms 'palliative care' and 'end of life care' are closely linked and can be used interchangeably, specialist palliative care has a broader role than end of life care. Specialist palliative care encompasses the period when people may be receiving palliative treatment for symptom control to improve their quality of life, and support for psychological distress and ethical issues in clinical decision making.

### 3. NATIONAL CONTEXT

3.1 The increase in the ageing population means that by 2030 the number of deaths will outnumber births. In addition people are living longer with serious illness. There is an anticipated significant increase in the number of people dying with and from dementia and an increase in the oldest of older people.

3.2 Approximately 500,000 people die in England each year, 99% of deaths occur in adults over the age of 18 years and most in people over 85 years. The majority of deaths occur following a period of chronic illness related to conditions such as heart disease, liver disease, renal disease, cancer, stroke, chronic respiratory disease, neurological disease and dementia.

3.3 People living their lives and yet facing death are seen in our community services, our GP surgeries, our hospitals, hospices and our urgent care settings. Many people are still benefitting from active treatment and support, however, we know that in the last year, months and days of people's lives, their need for care can change rapidly and unpredictably.

#### **One Chance to Get It Right, 2014**

3.4 The Leadership Alliance for the Care of Dying People (LACDP), which was established following an independent review of the Liverpool Care Pathway for the Dying Patient (LCP), published 'One chance to get it right' in June 2014. This focuses on care in the last days of life using 5 priorities of care:

- **Recognise** This possibility is recognised and communicated clearly, decisions made and actions are taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly;

- **Communicate**\_Sensitive communication takes place between staff and the dying person, and those identified as important to them;
- **Involve**\_The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants;
- **Support**\_The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible;
- **Plan & Do**\_An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

### **Actions for End of Life Care: 2014-16, NHS England**

- 3.5 NHS England has ‘ambitious plans to improve the care for people of all ages; people living with and dying from all conditions and those that need additional specialist help and advice’.

### **The Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020**

- 3.6 The National Palliative and End of Life Care Partnership, made up of statutory bodies including Public Health England, NHS England, the Association of Adult Social Services, charities and groups representing patients and professionals has developed a framework for action in making palliative and end of life care a priority at local level. It is aimed at local health and social care and community leaders. It builds on the Department of Health’s 2008 Strategy for End of Life Care and responds to an increased emphasis on local decision making in the delivery of palliative and end of life care services since the introduction of the Health and Social Care Act 2012.

- 3.7 This national framework for action sets out six ‘ambitions’ – principles for how care for those nearing death should be delivered at local level:

- each person is seen as an individual;
- each person gets fair access to care;
- maximising comfort and wellbeing;
- care is coordinated;
- all staff are prepared to care;
- each community is prepared to help.

- 3.8 The framework identifies measures such as personalised care planning and shared electronic records that are needed to realise each of the six

ambitions, and calls on Clinical Commissioning Groups, Local Authorities and Health and Wellbeing Boards to designate a lead organisation on palliative and end of life care and to work collaboratively to bring people together to publish local action plans based on population based needs assessments. Ambitions for End of Life Care:

[www.endoflifecareambitions.org.uk](http://www.endoflifecareambitions.org.uk)

### **Every Moment Counts**

- 3.9 The narrative for 'person-centred coordinated care' produced for NHS England by National Voices in 2014, in conjunction with its partners, sets out critical outcomes and success factors in end of life care, support and treatment, from the perspective of the people who need that care, and their carers, families and those close to them. These include honest discussion and the chance to plan, work to achieve individual goals and quality life and death, and for the people who are important at the centre of my support, physical, emotional, spiritual and practical needs and responsive, timely support day and night.

### **Reducing Inequalities**

- 3.10 The report Deprivation and death: Variation in place and cause of death demonstrates that socioeconomic deprivation is a factor not only in age and cause of death, but also place of death. Nationally, 61% of people living in the most deprived quintile die in hospital, compared to rates between 54-58% for people living in other quintiles, and this is true for each underlying cause of death. Conversely, people in the lowest quintile were least likely to die in a care or nursing home at 11% compared to other quintiles that vary from 16-20%. The proportion of deaths in hospices is also greatest for the least deprived.
- 3.11 People in the most deprived quintile die younger, with twice as many deaths of people under 65 in the most deprived compared to the least deprived.
- 3.12 The cause of death also varies with deprivation, with more people dying both from smoking related cancers of the lung, oesophagus, head and neck, bladder, cervix and liver and chronic respiratory disease in people living in the most deprived quintile. There are fewer deaths from malignant melanoma, breast and prostate cancer.
- 3.13 There is also growing national evidence that people from Black, Asian and minority ethnic groups have lower access to palliative and end of life care services.
- 3.14 The Care Quality Commission has undertaken a thematic project to understand the barriers which prevent people with the poorest experience of care from receiving good quality, joined up care at the end of life, whilst also identifying good practice.
- 3.15 In their published themed review of end of life care (October 2015) five new priorities for End of Life Care have now replaced the Liverpool Care Pathway (LCP) as the new basis for caring for someone at the end of their life. The new approach recognises that in many cases, enabling the

individual to plan for death should start well before a person reaches the end of their life.

- 3.16 The aim is to promote a stronger culture of compassion in the NHS and social care – one that puts people and their families at the center of decisions about their treatment and care

**Palliative Care Funding Review**

- 3.17 The White Paper *Liberating the NHS*<sup>4</sup> published in 2010 included the following text:

*“The previous administration made progress in developing payment by results in acute trusts. The mandatory scope has changed little since 2005/06, and has not incentivised results throughout the system. The Department will review payment systems to support end-of-life care, including exploring options for per-patient funding.”*

- 3.18 The national aim is to develop a classification system categorising palliative care patients according to need, and then to attach resource use and costs to each level of need, so supporting tariff development.

**Choice in End of Life Care**

- 3.19 In February 2015 the Choice in End of Life Care Board published a Review of Choice in End of Life<sup>5</sup> outlining clear recommendations for a national choice offer to be in place by 2020, alongside increasing the coverage of coordinating systems to 100% by 2018 and ensuring that 24/7 out of hospital care is in place by 2019. It also sets out the need for work to continue on outcome and experience measures and suggests that social care at the end of life should be free. It recommends that additional spending is identified to enable this in the next spending review.

- 3.20 In addition, the House of Commons Health Committee published their final report with respect to end of life care in March 2015, in which they focus on the need for providers to ensure they have a model in place to deliver the approach set out in ‘One Chance to Get it Right’. They also make a call to the Government to set out plans to enable sustainable hospice care, suggest that social care at the end of life should be free and that there needs to be focus going forward on outcome measures.

**NICE guidance Care of dying adults in the last days of life (2015)**

- 3.21 Published in December 2015, the NICE guidance covers the clinical care of adults (18 years and over) who are dying during the last 2 to 3 days of life. It aims to improve care for people by communicating respectfully and involving them, and the people important to them, in decisions and by maintaining their comfort and dignity. The guideline covers how to manage common symptoms without causing unacceptable side effects

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[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/213823/dh\\_117794.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213823/dh_117794.pdf)

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[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/407244/CHOICE\\_REVIEW\\_FINAL\\_for\\_web.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/407244/CHOICE_REVIEW_FINAL_for_web.pdf)

and maintain hydration in the last days of life. It is notable that artificial nutrition is not discussed.

3.22 The NICE guideline includes recommendations on:

- recognising when people are entering the last few days of life;
- communicating and shared decision-making;
- clinically assisted hydration;
- medicines for managing pain, breathlessness, nausea and vomiting, anxiety, delirium, agitation, and noisy respiratory secretions;
- anticipatory prescribing.

#### **National End of Life Care Intelligence**

3.23 Public Health England's National End of Life Care Intelligence Network is working towards a new national data collection from specialist palliative care services. The aim is to improve coordination of care through effective information sharing across healthcare organisations. The new data collection started in July 2016 from NHS and non-NHS hospital, hospice and community specialist palliative care services, with full implementation scheduled for April 2017. It is being supported by the development of a new national information standard (SCCI2036).

3.24 The purpose of the data collection is to improve outcomes for patients, carers and their families and to support the development of a new specialist palliative care funding model by NHS England.

3.25 The 'Palliative Care Co-ordination: core content' information standard aims to improve the co-ordination of care and sharing between providers through better communication of people's wishes and preferences for care at the end of life. It specifies the core content to be held in Electronic Palliative Care Co-ordination Systems (EPaCCS).

### **4. LOCAL VISION AND VALUES FOR END OF LIFE CARE CONTEXT**

4.1 In Somerset approximately 5,500 people die each year. Approximately three quarters of deaths are expected, so there is potential to improve the experience of care in the last year and months of life. In Somerset the total number of death has remained fairly constant from 2006 until 2014, followed by a small increase in 2015 (where all of Europe had a significant increase in deaths early in the year).

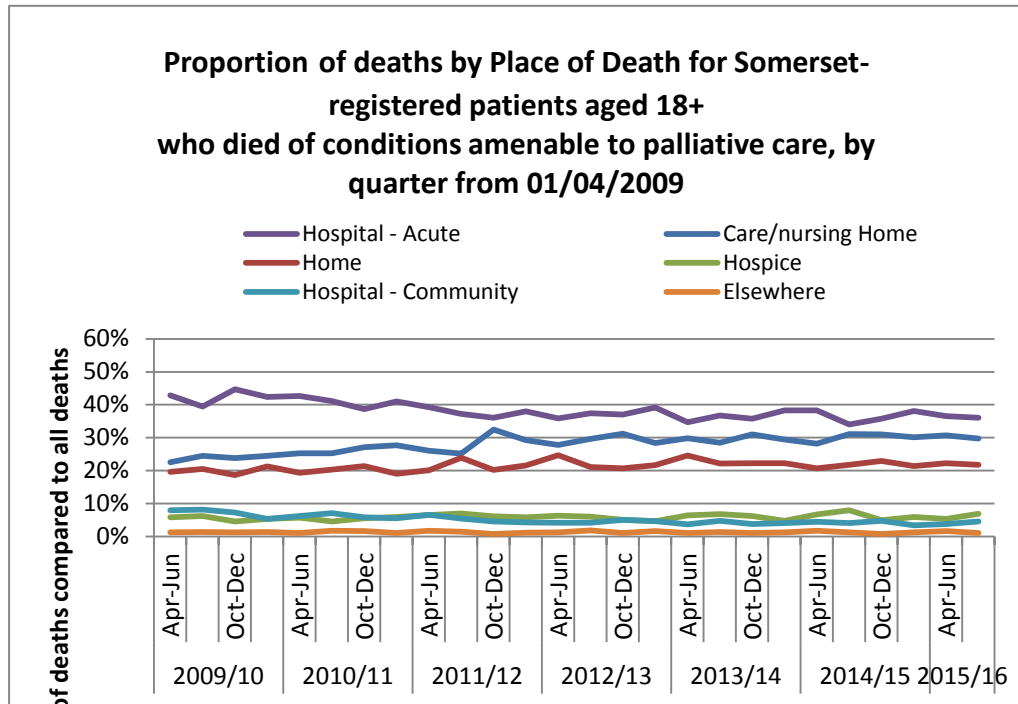
4.2 The number of deaths is expected to rise by 17% from 2012 to 2035. The percentage of deaths occurring in the group of people aged 85 years or more is expected to rise from 32% in 2003 to 44% in 2030. Approximately



three quarters of deaths are expected, so there is potential to improve the experience of care in the last year and months of life for this group.

4.3 Approximately one third of people will die from cancer, two thirds from a non-cancer diagnosis. People with cancer are more likely to die at home, those with cardiac, respiratory and cerebrovascular disease more likely to die in an acute hospital, and those with dementia to die in a care home.

4.4 The chart below shows the data on the Place of Death in Somerset from April-June 2009 to Jul-Sep 2015.



4.5 The National End of Life Care Intelligence Network produces rolling annual data for deaths in usual place of residence, (deaths in own home and care homes). Deaths in usual place of residence in Somerset:

2014/15 Q2-2015/16 Q1	51.9%
2014/15 Q1-2014/15 Q4	51.1%
2013/14 Q4-2014/15 Q3	51.5%
2013/14 Q3-2014/15 Q2	50.9%

4.6 We aim to commission end of life care to reduce health inequalities and enable equitable access to high quality end of life care for people from all communities, hard to reach groups e.g. the homeless, as well as those living with a learning disability, neurological condition or severe mental health problem. We also want to commission end of life care that improves patient experience by learning from patient feedback and complaints and improving coordination of end of life care particularly during out of hours periods which offer challenges to those needing, or trying to deliver, high quality end of life care.

- 4.7 The Department of Health further identifies the key steps of an end of life care model that we aspire to commission.
- 4.8 Achievement of this vision is dependent on a number of factors, not all of which are within our control:
- we need a society that has increased awareness and a more open attitude to discuss individual preferences for end of life care, together with empowered generalist staff facilitating open and honest communication with patients, recognising and acting when a patient is deteriorating and identifying those approaching the end of their life;
  - appropriately timed conversations about end of life care;
  - recording individual patients' preferences through care planning;
  - sharing of information/communication of Advance Care Planning.
- 4.9 The way we commission our services will be shaped by our values, which are:
- 4.9.1 **Putting the patient, and those close to them, at the centre of what we do.** This means listening to patients about what they want and what is important to them, designing our services around their needs rather than the needs of the services, and responding to their views
- 4.9.2 **Equity** - We want the highest standard of care for everyone in our population, and we will ask the views of people who may be more vulnerable, or find it more difficult to access services, in order to shape our commissioning and our services so they reach everyone in need.
- 4.9.3 **Partnership** - We will develop a culture of partnership, with patients and carers, and also with and between our providers, because we believe that patients will have a better experience in a co-ordinated system.
- 4.9.4 **Continued learning** - We will continuously seek to improve, and we will learn from our local experiences, listening to both patients and staff, and we will also seek to learn from good practice around the country.

## 5. CURRENT SERVICES

- 5.1 The following table summarises the End of Life Care and Specialist Palliative Care Services currently commissioned in Somerset. It must be noted that St Margaret's Hospice, Dorothy House Hospice Care and Weston Hospice are registered charities and receive between 19-26% income from NHS Somerset CCG.

PROVIDER	CURRENT SERVICE PROVIDED
<b>Musgrove Park Hospital</b>	<ul style="list-style-type: none"> <li>• Specialists Inpatient unit for cancer and non-cancer patients (Beacon Centre)</li> <li>• Taunton and Somerset Specialist Palliative Care team: specialist palliative care nurses with medical consultant cover from Somerset Partnership NHS Foundation Trust Palliative Care Consortium</li> <li>• The service sees both cancer and non-cancer facilitating end of life care and discharge to patient's preferred place of death</li> <li>• 24/7 on call advice by consultants and specialist registrar</li> </ul>
<b>Yeovil District Hospital</b>	<ul style="list-style-type: none"> <li>• YDH Specialist Palliative Care Team - one WTE CNS, 0.8 CNS and one WTE End of Life Discharge nurse, with medical Consultant cover from Somerset Partnership Palliative care Consortium (2 half-day sessions per week)</li> <li>• The service sees both cancer and non-cancer patients in all areas of the hospital from diagnosis to end of life care and facilitating end of life discharge to patients preferred place of care.</li> <li>• OOHs telephone advice provided by St Margaret's Hospice</li> <li>• The SPC team currently operate from Mon- Fri 0900 -1700</li> <li>• 7 day service provided by the CNS is currently under review</li> </ul>
<b>Royal United Hospital Bath</b>	<ul style="list-style-type: none"> <li>• The RUH has a Specialist Palliative Care (SPC) team – includes: lead nurse palliative and end of life care, CNSs in palliative care, OT palliative care, admin and medical support from Dorothy House Hospice Care with 5 consultant in palliative medicine/associate specialist PAs per week</li> <li>• OOHs telephone advice is provided by Dorothy House Hospice</li> <li>• The SPC team currently operates Mon-Fri 8.30 am - 4.30 pm</li> </ul>
<b>Somerset Partnership NHS FT</b>	<ul style="list-style-type: none"> <li>• Palliative Care Medical consultants</li> <li>• End of Life Care Coordination Centre</li> <li>• District Nursing Service - 24 hours</li> <li>• Community Hospitals providing end of life care</li> <li>• Older people's mental health wards</li> <li>• Integrated Rehabilitation Teams</li> </ul>
<b>St Margaret's Hospice</b>	<ul style="list-style-type: none"> <li>• Inpatient unit – 24 beds for cancer and non-cancer patients</li> <li>• Palliative care medical consultant</li> <li>• Day Hospice services in Taunton and Yeovil, with places available three days a week in each centre</li> <li>• Therapy services, including Physiotherapy, Lymphoedema, Complimentary Therapy, social work and occupational therapy</li> <li>• Community Specialist Palliative Care Nursing Team including non-medical prescribers</li> <li>• 24 hour central referral and Telephone Advice line</li> <li>• Bereavement and family support services</li> <li>• Sunflower Friends Volunteer service</li> <li>• Somerset cancer care support groups</li> </ul>

<b>PROVIDER</b>	<b>CURRENT SERVICE PROVIDED</b>
<b>Dorothy House</b>	<ul style="list-style-type: none"> <li>• Inpatient unit – 10 beds for cancer and non-cancer patients</li> <li>• Day Patient Unit 5 days a week at Dorothy House</li> <li>• Day Patient Services in Trowbridge and Peasedown St John</li> <li>• Therapy services, including Physiotherapy, Lymphoedema, Occupational Therapy, Complimentary Therapy and Integrated Palliative Medicine services</li> <li>• Community Specialist Palliative Care Nursing Team</li> <li>• 24 hour Telephone Advice line</li> <li>• Bereavement and Family Support Services</li> <li>• Hospice at Home Service</li> <li>• Education team</li> <li>• Volunteer Companion service</li> </ul>
<b>Weston Hospice</b>	<ul style="list-style-type: none"> <li>• Inpatient unit – 10 beds for cancer and non-cancer patients</li> <li>• Day Hospice 12 places per day three days a week</li> <li>• Community Specialist Palliative Care Nursing Team</li> <li>• Telephone advice line</li> <li>• Companion volunteer service both in hospice and in the community</li> <li>• Rehab. and therapies</li> <li>• Bereavement service</li> </ul>
<b>Marie Curie</b>	<ul style="list-style-type: none"> <li>• Intensive Home Nursing Service – night care service</li> </ul>
<b>NHS Somerset Continuing Health Care</b>	<ul style="list-style-type: none"> <li>• Fast Track Continuing Care Funding for End of Life Care Patients – for support in the home or care home available for eligible patients.</li> </ul>
<b>Care Homes</b>	<ul style="list-style-type: none"> <li>• A number of care homes in Somerset have accreditation for end of life care through the Gold Standards Framework</li> </ul>
<b>Somerset Lymphoedema Service</b>	<ul style="list-style-type: none"> <li>• Full range of lymphoedema management services provided by St Margaret's Hospices via clinics in Taunton and Yeovil and outreach clinics</li> <li>• Growing range of lymphoedema management services provided by Dorothy House Hospice Care for patients in the east of the county.</li> </ul>
<b>Local bereavement support</b>	<ul style="list-style-type: none"> <li>• A number of local and national charities provide support for patients and families including Cruse bereavement support.</li> </ul>

5.2 St Margaret Hospice Fit for Future is a wide ranging community engagement programme, bringing together leading healthcare experts, carers, national cancer charities, church leaders, academics, neighbouring hospices, politicians and the local authority, to assess the action that is required to support palliative care provision to meet the future needs of the population. It is a forward thinking review to increase

the level of co-ordination of palliative care provision in Somerset through the development of collaborative partnerships and community inclusion. It aims to co-design a sustainable care model that meets the needs and aspirations of patients, carers and other key stakeholders. This will be based on views from wide stakeholder engagement and analysis, backed up by desk top research will ensure an evidence base. The review Panel is due to report its findings by November 2016 and aims to provide a strategic blueprint for better and more efficient palliative care across Somerset for the next 5 to 10 years.

### **Generalist Palliative Care Services**

5.3 For many people, the majority of their care during the last year of life comes from generalist services such as GP practices, care homes, district nurses, hospital wards and outpatient departments and domiciliary carers.

5.4 It is therefore important to work with the providers of these services to ensure that the vision for end of life care is understood, and that staff have the appropriate skills and knowledge to meet the needs of individuals and their families and their wishes at the end of life.

### **Somerset Doctors Urgent Care**

5.5 On 1 July 2015 Somerset Doctors Urgent Care (SDUC), a part of the Vocare Group, took on the NHS 111 and GP Out of Hours (GP OOH) contract in Somerset. Call Advisors and Out of hours clinicians have access to the Somerset Electronic Palliative Care Coordination System, (EPaCCS). This system is key to improving the co-ordination and quality of care provided for people at the end of life.

## **6. PRIORITIES TO IMPROVE END OF LIFE CARE**

6.1 To deliver our local vision for end of life care, Somerset CCG will work in partnership with our local providers to reach agreed priority standards, taking collaborative ownership of agreed performance metrics.

### **Seeking views of user/carers**

6.2 Through the national Voices work, the national strategy set out national plans to seek the views of carers, including surveying bereaved relatives. Locally, there is a need for further development of mechanisms to enable the views of patients and carers to continue to influence commissioning for end of life care. A review of palliative care complaints over a 15 month period in 2013/14 indicated that the number of complaints was small compared to the number of deaths in Somerset, but may represent a larger number of people who had a poor experience of end of life care but whose relatives did not complain. Overall care in the out of hours period was the largest area of complaint as a result of challenges accessing out of hours GPs and district nursing, time taken to get adequate pain control in place out of hours and coordination of end of life care. As a result of this review further work was undertaken on both pathways and provision of end of life care during the Out of Hours period.

### **Assessing Needs**

6.3 We need to understand some of the local needs, further work is required to understand the impact of Somerset's changing population to build on the developing Joint Strategic Needs Assessment.

### **Strategic Priorities**

6.4 The themes in the National End of Life Care Strategy, recent policy and research documents, has enabled Somerset to identify local priority areas. There are areas such as bereavement support where there is scope for improvement and will need to be revisited as the planning to take this strategy forward develops.

### **Local Priorities**

#### **End of Life Care Local Priority Areas**

##### **a) Identification and care planning**

#### **Advance Care Planning**

Planning Ahead is the Advanced Care Plan document developed by Somerset CCG and the Somerset End of Life Clinical Programme Group and available for use across the healthcare community. It is available in a professionally printed format and also electronically on the GP desktop Pathway Navigator Palliative Care guide.

The CCG is committed to supporting greater use of advance care plans, and including those people on the palliative care register within its target group, irrespective of their diagnosis. This will include those with dementia with whom care planning for end of life may need to take place earlier. An important factor in the provision of good, person-centred end of life care is

the opportunity for a patient to discuss, agree and document their future wishes about their treatment and care.

Planning Ahead is patient owned and does not become part of the medical record or sent to any other organisation. Initially use of this booklet was targeted at patients believed to be in their last year of life. Over the next 5 years its use will be extended to a wider group of patients including all those with a Long Term Condition and those over the age of 75 years.

#### **General Practice Palliative Care Registers**

General Practices have a variable process of good coordination of care and often patchy Gold Standard Framework (GSF) / palliative care meetings. The CCG has obtained funding in 2016 to work with Practices to help them identify more patients who may die in the subsequent 12 months, and to address their needs for planning for end of life care more proactively. Not all practices maintain their own register of palliative care patients, and review these regularly this needs further support.

### **Dying Matters**

At the same time as training professionals, there is a need to encourage the general population to plan for their own deaths, and the CCG supports the national Dying Matters Campaign every year, as well as using available opportunities to promote the message through representation at public meetings, website information, and partnership work with other agencies. Somerset CCG has started a work programme on introducing frailty assessment as a recognised long term condition, using a frailty score such as the Rockwood to enable clinicians to start to help individuals and their families plan ahead. Within this work programme there is an increasing emphasis on the value of commencing Advance Care Planning as early as possible in order to help these patients to discuss and document their wishes about their future care.

A key priority area is the development of a Public Health approach to palliative care. The CCG will work with other organisations to develop Compassionate Communities in Somerset, with the aim of Somerset becoming a Compassionate Community.

### **Do not attempt cardiopulmonary resuscitation - DNACPR**

The development of an agreed DNACPR form across Somerset has been a major step forward, but there is a need continually to update training for all relevant staff, and to keep up to date with best practice.

### **Treatment Escalation Plans (TEPs)**

Acute Trusts are now using TEPs that indicate a ceiling of treatment for individual patients. It is always a Health Professional's duty to act in a patient's best interest. All treatment and care that is appropriate for a patient will be offered, but as a patient approaches the end of their life active treatment may be deemed less beneficial and the focus of care will move from cure to optimising symptom control, well-being and facilitate healing in accordance with their stated wishes. The National Resuscitation Council is developing a national TEP form, and once this is published, the End of Life Programme Group will review this, in discussion with the CCG Urgent Care Group, to determine if this would be suitable for use in both acute and community settings in Somerset.

### **Out of Hours (OOH)**

We need to improve care coordination and access to care and health professionals in the out of hours period, not through NHS 111 but by direct access to health care professionals who are involved in the individuals care.

## **b) Communication and co-ordination**

### **Advanced Communication Skills**

There is an expectation that all staff caring for Palliative and End of Life patients will undertake communication skills training and that training updates commensurate with their role and required level of competency and that training will be provided on a regular basis.

### **Electronic Palliative Care Co-ordination System, (EPaCCS)**

There is national requirement for CCG's to have an EPaCCS. EPaCCS enables the recording and sharing of people's care preferences and key details about their care at the end of life. It is a vital tool to support the implementation of personalised care plans and helps to reduce in appropriate / unwanted hospital admissions at the end of life.

There is an expectation the provider of this system will maintain the requirements of the national information standards and any subsequent national or local development needs. This system is currently provided by Somerset Doctors Urgent Care Service.

### **Discharge from acute care**

All acute trusts should have arrangements in place to support timely discharge and ensure access to end of life care at home and the rapid coordination of discharge to home with care package, through involvement of family and carers. This should be supported by advance care plans and exploration of the of a personal health budget as this project is implemented.

### **Co-ordination of care at home**

A key identified need is for greater co-working between both Somerset County Council commissioned domiciliary care services and CHC commissioned domiciliary care services and other services supporting people, at home. The development of integrated team working with district nursing, specialist palliative care nurses and domiciliary carers to provide coordinated end of life care with an identified lead professional for all individuals and their families at end of life is vital. We will continue to work with the existing home care providers, and identify opportunities to pilot new ways of working.

### **Somerset Together**

Integrated commissioning between health and social care provides opportunities for improved quality in end of life care through more integrated working to meet the needs of patients and their families. This will include personalised end of life care plans provided for all, wherever possible.

### **Single shared documents and care plans across the healthcare community:**

#### **Communication System (CCD)**

Somerset has a communication system that is used by clinicians in the acute trust when a person is identified as at end of life, and this will be enabled to communicate, together with suggested focus of care, to general practice.

### **c) Quality of care in the last days and hours of life and in bereavement**

NICE Care in the last days of life and 'One Chance to get it Right' gives



guidance on the quality standards with a clear focus on the discussions to be held with the patient and family.

All staff engaged in end of life care, both specialist and generalist must have knowledge and expertise in delivering sensitive and compassionate end of life care for patients and their families.

The Compassionate Community Project in Somerset has set a 10 year plan, which includes an aspiration to raise the rate of deaths for people who choose to die at home to 50% by 2026. The focus for this project is initially in the Frome area, with subsequent roll out to other areas. In Frome there have already been significant projects in community development for vulnerable people with chronic health problems, including formation of available community resources, formation of new groups when there is a gap, working with neighbourhoods, linkage with local councils, working with individuals on a one to one basis to try and work through their priorities and linkage with GP practices. This model of care is readily adaptable to end of life care and further initiatives are planned, including

- community initiated and led advance care planning;
- community network development skills;
- manual handling training for communities;
- training people and families how to give injections for symptom control needs;
- support for those important to the dying person, before, during and after death, is important to enhance resilience and return to societal function. Most will have a healthy grief process without professional input but some will need specialist support. The CCG will engage with the End of Life group to review how such services are currently arranged and if, as commissioners, they have a role in improving these services or service commissioning.

#### **d) Education and training**

- the key to good quality end of life care is staff that are trained in the knowledge and expertise to provide high quality compassionate end of life care. This training should focus both on advanced communication skills training as well as symptom control and coordination of care;
- ensuring that staff are supported in delivering high quality end of life care and have access to clinical supervision in delivering this demanding role is vital;
- we are committed to continuing and expanding this training to include both NHS staff in primary care, community services, mental

health care and generalist medical care, together with domiciliary care staff, care home staff, and staff providing Continuing Health Care;

- we acknowledge the need for a tailored approach as needs differ across the workforce, but wherever possible training will be undertaken together i.e. across organisational and functional boundaries;
- appropriate level of advanced communication skills training for all staff involved with dying people and their carers;
- carer support is essential to dying at home. Carers may be professional or lay persons. They require a needs assessment, care and support, and appropriate level of information to prepare them for caring for their loved one at the end of life. The CCG will review current levels of care support and work, through integrated collaboration, to improve the support of carers of those who are dying.

#### **e) Carer Support**

Family members and other carers often make a significant contribution to the provision of end of life care. We will seek to ensure that carers are involved and engaged in decisions about the care of the patient and also that the carer's own needs are understood. Every carer should feel

well supported and be encouraged to address their own physical, practical, emotional and spiritual needs.

Bereavement support will be offered to family members and other carers following the death of a patient in a timely and appropriate manner.

#### **Equality and Equity of access**

There is evidence that people with mental health problems, people with learning difficulties and from more deprived communities have lower access to end of life care services: we will seek to learn from the CQC review of end of life care and good practice elsewhere, on how we can ensure that Somerset provides fair and equitable access.

Somerset as a rural community should also extend the reach of palliative care services, particularly to rural areas, hard to reach and seldom heard groups through our engagement strategies.

#### **Service User and Carer engagement**

We will work with our provider organisations to develop ways of gaining patient and carer views as an integral part of the way we work and in a collaborative manner as appropriate.

We will comply with the Duty of Candour, 2014, to be open and honest with patients as well as being open and honest to report adverse incidents or near misses that may have led to harm.

We will develop improved ways to develop carer feedback on their experience of end of life care.

We will act on feedback from patients, carers and health professionals and instigate case reviews as necessary to examine lessons learnt and make recommendations to change practice to improve end of life care in Somerset

## **7. DELIVERY**

- 7.1 In order to deliver this strategy and realise the benefits for users and carers a more detailed implementation plan will be developed by the Somerset CCG End of Life Care Programme Board. The plan will work to ensure best use of the existing resources, building on what has been done to date and where necessary develop specific project mandate(s) to take collaborative improvement work forward.
- 7.2 Each organisation from across the Somerset healthcare community which is represented on the Somerset CCG End of Life Clinical Programme Group will be asked to commit to provide an annual organisation plan to describe how they will contribute to the implementation of the Somerset strategic objectives.
- 7.3 In 2016-17, in addition to maintaining the current level of services for end of life care, the plan is to:
- increase the use of Advanced Care Plans (ACP) and increase the number of people able to die in their usual place of residence through delivery of advance care planning training with a focus on primary care in 2016 – 17;
  - improve coordination of care and ensure each patient and their family has an identified lead professional for their end of life care;
  - ensure sharing of information of patients wishes and consider the best platform for EPaCCS;
  - use of digital technology particularly to address access to timely advice and support in rural areas;
  - developing a programme dashboard to including number of days spent in acute hospital in the last year of life;

- the CCG and providers to become Compassionate Organisations and support the development of Compassionate communities;
- develop a communication plan to promote Dying Matters and conversations and planning for end of life in our communities;
- further develop appropriate ways to hear patient stories, and implement the learning from them;
- update Somerset End of Life Care website<sup>6</sup>. A short life working group will focus on content and accuracy. It will also explore use of Somerset Choices and whether Somerset Choices will become the preferred access point for end of life services and information Place of death is not a marker of good end of life care;
- it is disappointing that there is no significant change in place of death in Somerset, and deaths in usual place of residence may have reduced slightly. The Clinical Programme Group needs to address ability to comply with wishes stated in advance as a matter of urgency;
- consider as a Somerset wide community the strategic direction for end of life care, the outcomes and recommendations from the Somerset wide Fit for Future review being led by St Margaret's Hospice and how this will fit with the Somerset Sustainability and Transformation plan;
- implement a pilot project for personal health budgets in end of life care;
- recommission domiciliary care services jointly with Somerset County Council in line with the Somerset end of life care strategy.

#### **Outcome Indicators**

7.4 Performance data will be collected on a quarterly basis and collated on the End of Life Care performance dashboard. Performance data will be collected from the following five sources:

- Patient and Carer feedback – we will use healthcare professional feedback and PALS concerns and complaints and we will also develop a local carer survey for feedback on end of life care at home and in care homes our local hospitals and hospices;
- Hospital Episode Statistics – acute hospital admissions during a patient's last year of life;
- Public Health data – number of deaths, place of death and diagnosis;

- EPaCCS data – number of patients on End of Life register and details of Advance Care Plan wishes and achievements.

## **8. REVIEW AND ACCOUNTABILITY**

8.1 Progress against the implementation plan will continue to be monitored by the End of Life Care Programme Board which is chaired by the CCG GP Clinical Lead for End of Life Care and includes representation from:

- Taunton and Somerset NHS Foundation Trust;
- Yeovil District Hospital NHS Foundation Trust;
- Somerset Partnership NHS Foundation Trust;
- St Margaret's Hospice;
- Dorothy House Hospice Care;
- Weston Hospice Care;
- South West Ambulance Service Foundation Trust;
- Somerset Doctors Urgent Care;
- Registered Care Providers Association;
- Public Health (County Council);
- Macmillan Cancer Support;
- Marie Curie;
- Lay representation;

## **9. RECOMMENDATIONS**

9.1 The development of a multiagency implementation plan to enable continued delivery of the Strategy (informed by the EIA). The plan will include where appropriate aspects to be taken forward through integrated commissioning mechanisms.

9.2 Review of the oversight and implementation plans for delivery of the Somerset End of Life Care Strategy with the Somerset Sustainability and Transformation Plan team as delivery may best sit as a workstream under the STP programme delivery board in the future.

## **10. REFERENCES**

National End of Life Care Strategy Department of Health July 2008

End of life care strategy Fourth Annual Report Department of Health  
October 2012

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End of Life Care intelligence network (2012)

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‘Once Chance to get it Right’ Leadership Alliance for the care of Dying  
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House of Commons, Health Committee Final Report End of Life Care,  
March 2015

The Ambitions for Palliative and End of Life Care: A national framework  
for local action 2015-2020

NICE guidance Care of dying adults in the last days of life (2015)

