



# Isle of Wight End of Life Care Strategy 2015–2020

*A partnership approach to the integrated provision of End of Life Care services on the Isle of Wight.*





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Embed good end  
of life care as  
everyday practice –  
make it everyone's  
business.

Isle of Wight End of Life Care Strategy Workshop,  
November 2014

## Foreword

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End of life care is one of our few certainties.

In the words of Leonardo Da Vinci, *“A well-spent day brings happy sleep, so a life well used brings happy death”*.

I wish end of life care was that easy!

End of life care is often difficult, although also rewarding if done well.

I hope that you will find the information and aspirations in this document a useful guide to improving care for those nearing the end of life.

Many surveys have indicated a growing wish by those approaching the end of life to die with the comfort and support of their families and loved ones, in their own homes rather than in hospital. I hope that the changes and developments outlined in this paper will make this easier to achieve.

We also want to improve the care provided for those who are approaching the end of life in healthcare settings.

Some of these improvements can be made through improved recognition of the fact that patients are reaching their last year of life. Other improvements can be made by encouraging healthcare staff and others to be brave enough and to receive the training to have difficult conversations around preferences at the end of life.

We are indebted to all those who have contributed suggestions for improvements and who are already changing their own practices to try to provide the highest standards in end of life care. Among these are ambulance staff, community nursing teams, IT support, medical teams, the Hospice, the CCG, the Council, primary care, and many others.

Macmillan has also been tremendously supportive with advice and resources to help to develop the Earl Mountbatten Hospice Community team.

I hope that everyone will be able to make use of the excellent ideas and aspirations in this document.

**David Isaac**  
**GP**

**End of Life Care Clinical Commissioning Group Lead**



**“I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s).”**

**Quote from ‘Every Moment Counts: A new vision for coordinated care for people near the end of life calls for brave conversations’.<sup>1</sup>**

## Executive Summary

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The aim of the End of Life Care Strategy 2015–2020 for the Isle of Wight is to help those with advanced, progressive and incurable illness to live as well as possible until they die, regardless of their diagnosis; to support individuals and their carers through the prevention and relief of suffering through early identification and assessment, effective treatment of pain and other symptoms, and the provision of psychological, spiritual, social and practical support. This strategy reflects the local needs of the Isle of Wight population and the national end of life care directives.

In developing this strategy we have reviewed the care that we deliver for dying people against the five priority areas set out by the Leadership Alliance for the Care of Dying People (LACDP)<sup>2</sup> and have considered how we will demonstrate delivery of each of these for individual dying people and those important to them. We have considered a broad range of national literature (see **Appendix 1**) including NHS England's Actions for End of Life Care 2014–16, the NHS Five Year Forward View and the End of Life Care Ambitions Partnership's 'Shared Vision for Better Care 2015–2020'.

Many improvements have been made in end of life care since the introduction of the national End of Life Care Strategy in 2008, and the Isle of Wight's End of Life Care Strategy in 2009, not least of which is a national increase in the numbers of people dying in their usual place of residence from 38% in 2008 to 44.5% in 2014, with the Isle of Wight achieving 48% in 2013/14<sup>3</sup>. There have been significant changes in the health and social care landscape in the intervening years which have prompted a re-evaluation of strategies, both local and national..

An End of Life Care Review conducted in 2014 evaluated current end of life care services on the Isle of Wight and identified potential service developments. Workshops held in November 2014 and July 2015, brought together a wide range of stakeholders from across the Island to identify and develop the aims and objectives of the Isle of Wight's End of Life Care Strategy.

The key recommendations include:

- Review end of life care on the Island against the Leadership Alliance for the Care of Dying People (LACDP) five priority areas and consider how we will deliver each of them for individuals and those important to them.
- Develop holistic and co-ordinated Island-wide end of life care offering a 'menu of choice' – an individualised journey within one integrated system of care across the whole health and social care system.

- Increase public awareness around end of life, encouraging culture change to enable good conversations to take place and ensure good access to information to allow informed planning.
- Train, support and empower staff, give them the confidence to identify and care for those at the end of their lives, and the tools to communicate clearly and sensitively with individuals and those important to them, including them in any decisions about their care. Embed this training as mandatory for all staff, committing organisational priority and resources.
- Implement the necessary systems to enable rapid, 24/7 access to end of life care with the right resources in the right place, allowing those at the end of their life to die in their place of choice and to ensure that they and their carers/families are fully supported in that choice.
- Develop one individualised care plan, agreed with the person and their carers/families, and a shared, person-held record: regularly reviewed, easily updated, easily accessed and visible to all who need to see it.
- Assign a dedicated keyworker to each person, to coordinate and review their care across all services in all settings and develop fast-track processes to access continuing care for those nearing the end of life.

The recommendations set out in this strategy support both the five priorities for end of life care, published in the LACDP's 'One Chance to Get It Right' (June 2014), and the six ambitions set out in 'Ambitions for Palliative and End of Life Care: A national framework for local action 2015–2020' (September 2015). Significant progress has already been made with many of these recommendations.

The End of Life Care Strategy should cover the needs of all people at the end of life, embedding end of life care as everyday practice across the Island's health and social care economy – make it everyone's business.



## 1. Introduction

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### 1.1 Overview

End of Life Care is a key priority for the Isle of Wight. The changing health and social care landscape has necessitated a review of our local end of life care services and prompted the development of an up to date strategy for end of life care on the Island, to reflect the current and future needs of the population and ensure that excellent end of life care is available to all.

The End of Life Care Strategy 2015–2020 for the Isle of Wight has been developed in line with national initiatives and local need, as highlighted in the Isle of Wight's Joint Strategic Needs Assessment (JSNA) and the Five Year Health and Social Care Vision:

- To support early recognition of those who are likely to die within the next 12 months.
- Enhance the coordination of services.
- Promote quality care, ensuring that as many people as possible live as well as possible until the end of their life and die in their preferred place of choice.

In developing this strategy we have reviewed the care that we deliver for dying people against the five priority areas set out by the Leadership Alliance for the Care of Dying People (LACDP)<sup>4</sup> and have considered how we will demonstrate delivery of each of these for individual dying people and those important to them. We have considered a broad range of national literature (see **Appendix 1**) including NHS England's Actions for End of Life Care 2014–16, the NHS Five Year Forward View and the End of Life Care Ambitions Partnership's 'Shared Vision for Better Care 2015–2020'.

This strategy has been informed by findings from the Isle of Wight End of Life review, published in March 2014 (see **Appendix 2**), and outcomes from the End of Life Care Workshop, held in November 2014, and will build on recent local and national developments to identify the next steps in providing high quality, coordinated end of life care through an integrated local health and social care system.

Significant progress in understanding end of life care pathways on the Island has been made in the last 12–18 months and will continue to be developed under this strategy.

With an overarching objective to provide end of life care tailored to the personal, cultural and spiritual values, beliefs and practices of the individual and their family/carer, end of life care will encompass support for family, friends and carers up to and including the period of bereavement.

The aims of this strategy are to:

- Improve the quality of end of life care for people on the Isle of Wight.
- Improve access to end of life care services, improve choice and reduce inequalities.
- Increase the number of people who are cared for and die in their preferred place.

The objectives of this strategy are to:

- Improve early identification of people nearing the end of their lives to enable better planning and co-ordinated care that helps support individuals and their carers to prepare for death.
- Improve communication and awareness around end of life care and promote the use of care planning to enable those identified as approaching end of life, and those important to them, to state their wishes and ensure they are adhered to.
- Improve the coordination and integration of end of life care to create an individualised journey within one integrated system of care, with easily accessible, shared patient records and care plans.
- Improve access to rapid response 24/7 end of life care, developing a single point of access and the resources required to provide it.
- Ensure high quality training and education is available for all staff groups, underpinned by competency frameworks, so that end of life care becomes everyone's business.
- Ensure that people approaching the end of their life, their carers, families and staff, have their physical, psychological, social and spiritual needs safely, effectively and appropriately met during the day and at night.

High quality end of life care would mean the following:

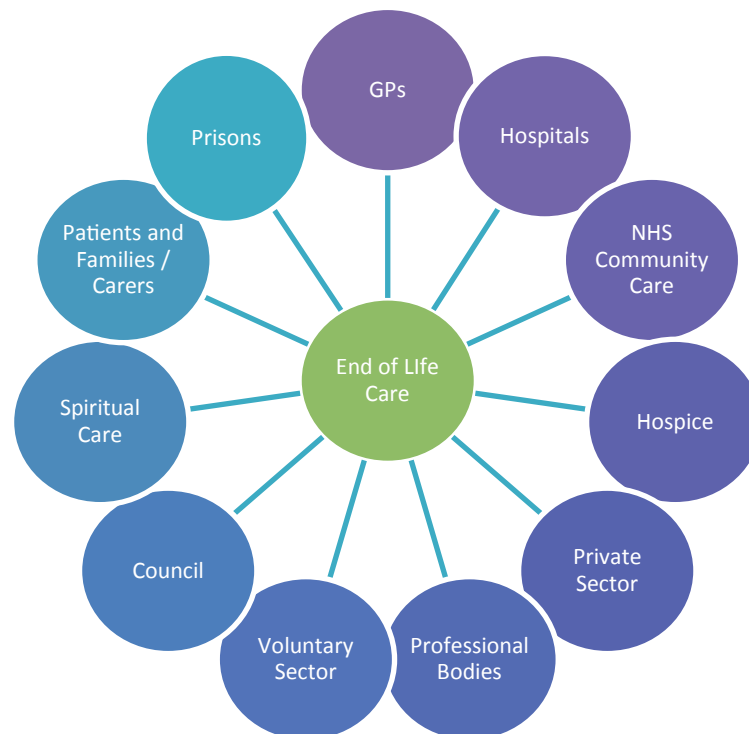
<b>The Public</b>	People will have high quality end of life care regardless of diagnosis, feel comfortable talking about death and dying and confident in making end of life care decisions. Their emotional, social and spiritual needs will be met and bereavement support will be available.
<b>Clinicians</b>	All Clinicians in primary and secondary care will be supported and resourced to ensure they are competent and confident to discuss death and dying and to provide generalist palliative care. Specialist palliative care will be available to those who need it.
<b>Commissioners</b>	Commissioners will be adequately informed of areas that require support and redesign to improve end of life care facilities and equipment, including service improvements.
<b>Health, Social Care and Care Professionals</b>	All Health, Social Care and Care Professionals will be competent and confident to provide care for people nearing the end of their life.

## 1.2 Definition

For the purpose of this document, we have used the working definition of ‘end of life care’ used in the original Department of Health National End of Life Care Strategy 2008, i.e. ‘the last year of life’. In doing so, we fully acknowledge that the progression of different conditions means that for some, ‘end of life care’ refers to the last few years of life, whereas for others, this could be a matter of months, weeks, days or hours. In the case of sudden unexpected death, the predominant focus of ‘end of life care’ may be on the period following death.

## 1.3 Core Service Areas

Good end of life care is to be embedded as everyday practice across the Island’s health and social care economy.



The Isle of Wight’s End of Life Care Strategy will link closely with a number of key strategies and work programmes including the Island’s Dementia Strategy. Issues around parity of esteem in end of life care will also be addressed to ensure that physical and mental health are equally valued and people have equitable access to services.

## 1.4 National drivers for change

NHS England's mandate from the government for 2015–16<sup>5</sup> includes an objective 'to pursue the long-term aim of the NHS being recognised globally as having the highest standards of caring, particularly for older people and at the end of people's lives'.

Domain four of the NHS Outcomes Framework 2015/16: Ensuring that people have a positive experience of care requires that there is 'improvement in the experience of care for people at the end of their lives' using bereaved carers' views on the quality of care in the last 3 months of life as an indicator.

Around 455,000 people died in England in 2010, two-thirds of whom were 75 years of age or older<sup>6</sup>.

Deaths in England and Wales are expected to rise by 17% from 2012 to 2030<sup>7</sup>.

In 2011, around 355,000 people need good palliative care services every year but around 92,000 people are not being reached<sup>8</sup>.

National Survey of Bereaved People (VOICES) 2013 found that:

- Overall quality of care has not changed significantly between 2011, 2012 and 2013.
- Quality of care was rated significantly lower for people who died in a hospital, compared to people dying at home, in a hospice or care home.
- For those dying at home, the quality of coordination of care was rated significantly lower in 2013 compared to 2012.
- The dignity and respect for patients shown by hospital nurses and hospice nurses has increased between 2011 and 2013.
- Pain is relieved most effectively in the hospice setting (62%) and least effectively at home (18%).
- Only half of people (50%) who express a preference to die at home, actually die at home.

There have been improvements nationally in place of death: 2012 was the first year in many years that the proportion of people in England and Wales dying in hospital dropped below 50% (49.5%), with 22% of people dying at home, 20% in care homes, and 6% in hospices<sup>9</sup>. Interestingly, whilst this has been an important driver for improving end of life care at home, the 'place of death' is not necessarily the highest priority for everybody: in a population-based study involving just under 10,000 adults across England, only 34% ranked 'dying in preferred place' as their top care-related priority; the rest were split fairly evenly between 'having as much information' as they wanted and 'choosing who makes decisions' about their care<sup>10</sup>.

In the 2012 British Social Attitudes survey, 60% of those who stated that they would prefer to die at home would change their mind if sufficient support from family, friends or social and medical professionals were not available<sup>11</sup>. The need to be pain-free (24%) came a close second to the presence of family and friends (28%), in terms of the most important aspects of their end of life care.

Traditionally, end of life care services have been orientated towards cancer care; however, people with a whole range of other conditions including cardiovascular, respiratory, neurological disorders and dementia should also be accommodated. In 2010 non-cancer related deaths accounted for over 70% of deaths<sup>3</sup>. Although the percentage and number of people with non-cancer diagnoses accessing specialist palliative care services<sup>12</sup> has increased overall in the past 12 years, the proportions of people with conditions other than cancer who access these services still remains very low. The proportions ranged from 10% for inpatient and home care specialist palliative care services to 25% for outpatient specialist palliative care services.

The Department of Health National End of Life Care Strategy 2008<sup>13</sup> outlined a series of steps to enable the delivery of quality End of Life Care as illustrated in Figure 1 below.

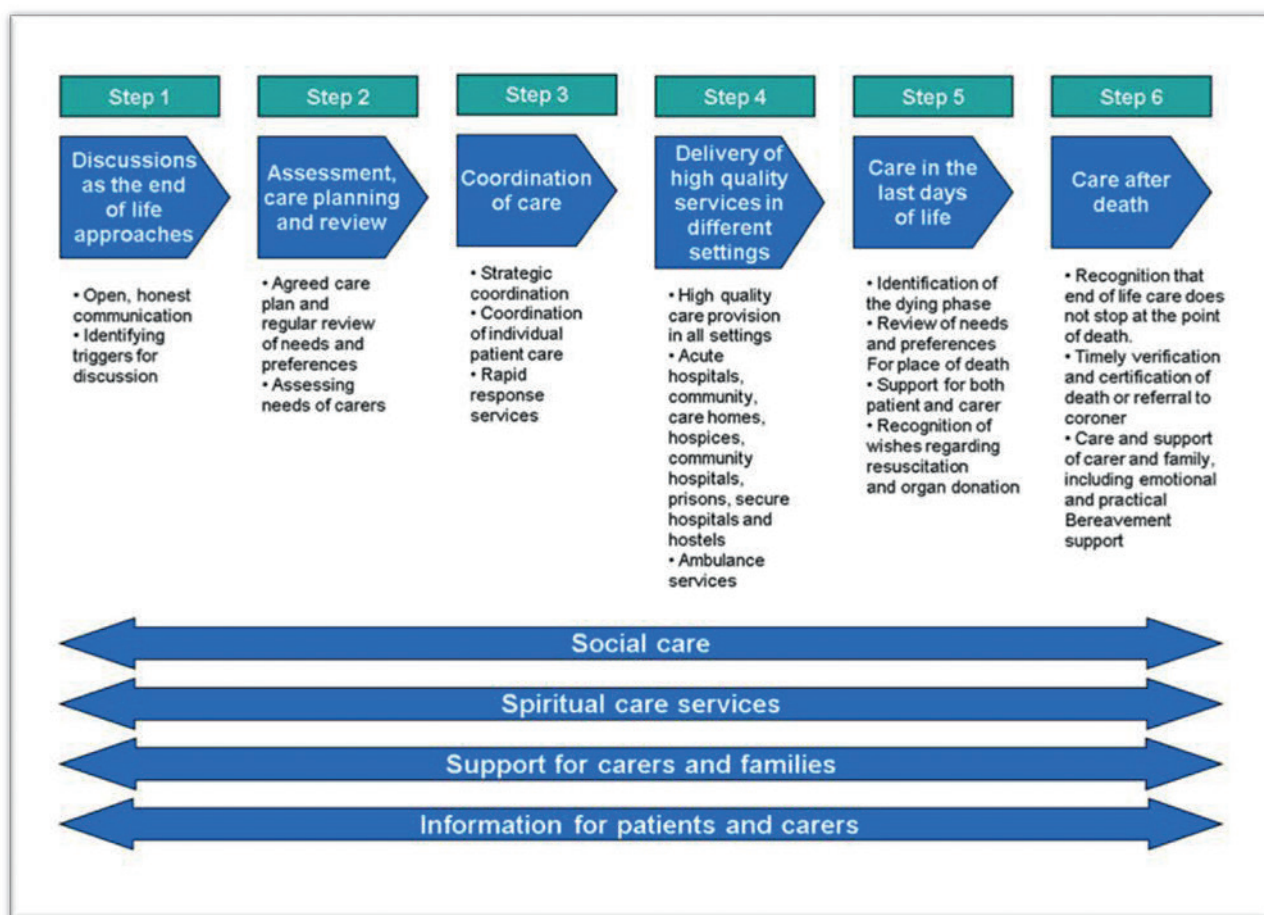


Figure 1: End of Life Care Pathway from DH Strategy 2008

In recent years a number of pathways were introduced to support the implementation of the National End of Life Care Strategy. In July 2013, the independent review of the Liverpool Care Pathway (LCP), *More Care, Less Pathway*<sup>14</sup>, found that where the LCP was used appropriately, many people died peaceful and dignified deaths but that in some cases, the LCP had come to be regarded as a generic protocol and was inappropriately used. The review recommended that the use of the LCP be phased out within 6–12 months.

In response to the report, the LACDP was set up to lead and provide a focus for improving the care for individuals and their families. In June 2014 the LACDP published 'One Chance to Get It Right' which sets out five priorities for end of life care (Figure 2, below) which align with the NICE Quality Standards Programme for End of Life Care for Adults 2011.

The Priorities for Care are that, when it is thought that a person may die within the next few days or hours:

**PRIORITY 1:** The possibility that a person may die within the coming days and hours is recognised and communicated clearly, decisions about care are made in accordance with the person's needs and wishes, and these are reviewed and revised regularly.

**PRIORITY 2:** Sensitive communication takes place between staff and the person who is dying and those important to them.

**PRIORITY 3:** The dying person, and those identified as important to them, are involved in decisions about treatment and care.

**PRIORITY 4:** The people important to the dying person are listened to and their needs are respected.

**PRIORITY 5:** Care is tailored to the individual and delivered with compassion – with an individual care plan in place. This priority includes the fact that a person must be supported to eat and drink as long as they wish to do so, and their comfort and dignity prioritised.

*Figure 2: The Five Priorities for Care, LACDP*

There is no intention to replace the LCP with a new national tool, so professionals will be expected to demonstrate attention to these five priority areas; service providers and commissioners are required to create and support the systems and learning and development opportunities that enable these priority areas to be implemented locally. Organisations and professionals will, as part of best practice, be expected to review the care they deliver for dying people against these five priority areas, including consideration of how they will demonstrate delivery of each of them for individual dying people and those important to them.

The LACDP five priority areas inform the inspection by the Care Quality Commission (CQC) of end of life care in acute hospitals, hospices, adult social care, community health services and general practice, and the development of new NICE Clinical Guidelines on the care of dying adults.

Other national drivers include the Care Act 2014<sup>15</sup>, which has impacted the delivery of social care, and a comprehensive raft of reports coming out of The Commission into the Future of Hospice Care<sup>16</sup> published by Hospice UK in 2013.

The NHS Five Year Forward View envisages that 'end of life care... will increasingly be provided in community settings'. NHS England has also set out a number of commitments in its Actions for End of Life Care 2014–16, to lead or influence its partners in improving end of life care to:

- Improve the way individuals and those close to them can feel informed, supported and engaged in their own care.
- Help health and care professionals build and sustain their commitment to working in partnership with each other, and with the people they care for and those close to them.
- Support staff, service providers and commissioners to develop or gain access to systems and processes that help them to deliver as good as possible experience of person-centred coordinated care for people in the last years of life, and those close to them.
- Develop resources and mechanisms to improve the commissioning of palliative and end of life care services so that people living with progressive, life-limiting conditions, and those close to them, can receive the best possible care that matches their level of need and, as far as possible, preference.
- Work collaboratively with strategic partners, community groups and other organisations throughout the health and care system to facilitate partnership working across the end of life care community, identify inequalities in end of life care, promote the use of 'Every Moment Counts', support the Dying Matters Coalition and support Public Health in its work to promote and assess the impact of the Public Health toolkit.

The End of Life Care Ambitions Partnership, consisting of a wide-ranging group of national organisations with experience in end of life care, has been reviewing all that they know about the delivery of end of life care, setting out ambitions for end of life care in their 'Shared Vision for Better Care 2015–2020'. In September 2015 'Ambitions for Palliative and End of Life Care: A national framework for local action 2015–2020' was published.



The EOLC Ambitions Partnership have stated an overarching vision: *“I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s).”* The six ambitions that have been set out to help achieve this vision are clearly supported by the recommendations in this strategy.

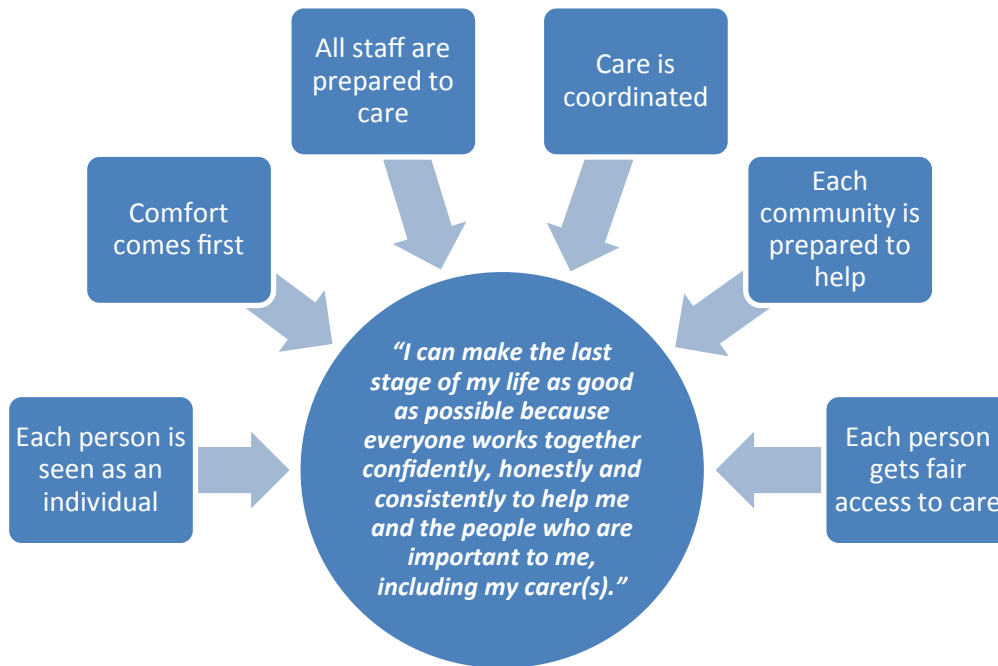


Figure 3. EOLC Partnership Six Ambitions for EOL Care

### 1.5 Local drivers for change

A number of issues arose during 2013 in relation to end of life care services on the Isle of Wight, including concerns over accessibility to the hospice, Occupational Therapy support (in both the hospital and hospice), pharmacy support to the hospice, and pathways across the whole of end of life care. This prompted a review and evaluation of the Isle of Wight Clinical Commissioning Group (IOW CCG) commissioned end of life care services against national guidelines, local End of Life Care Strategy, provision of local hospice care and current pathways of care.

The review, undertaken in early 2014, included face-to-face interviews with key stakeholders, an analysis of data and information relating to Isle of Wight end of life care services and an examination of good practice nationally. The findings of this review, including how we can learn from best practice in other areas such as Torquay, Greenwich and Somerset, were published in March 2014, and have informed this strategy and its recommendations.



The 2014 CQC report on the Isle of Wight NHS Trust, while recognising some areas of good practice, such as *'Staff are competent in how to recognise when a patient is on an end of life journey, so that decisions are made and their care managed appropriately'* and some patients reporting *'a good experience of end of life care'*, also highlighted areas where the Trust was required to make improvements in the provision of end of life care, such as inconsistent use of documentation, inadequate recording of discussions and decisions made at end of life, lack of training, lack of identification of people approaching the end of life and lack of planning, including use of the Amber Care Bundle (ACB), a multi-disciplinary tool to support staff in identifying and managing people whose recovery is uncertain, and may be at risk of dying in the next one or two months. The Trust has identified the use of the Amber Care Bundle as a key theme in their Quality Improvement Plan.

An End of Life Care strategy workshop held on 6<sup>th</sup> November 2014 brought together a wide range of stakeholders from across the Island, focusing on how the provision of end of life care on the Island could be improved, and to identify and develop the aims and objectives for this strategy.

The Island performs well in some areas, such as numbers of people who die in their preferred place of death, however:

- The IOW has a high length of stay for people who die in hospital.
- The IOW has the highest percentage of deaths from Dementia in England.
- The IOW spends more on EOLC than the national average<sup>17</sup>.

## 2. Where are we now?

### 2.1 Current Services

Over time, mortality rates from all causes on the Island have fallen significantly from 568.1 per 100,000 in 2003–05 to 516.2 per 100,000 in 2008–10 and have consistently remained below the England average.

The highest major cause of deaths on the Island in 2011 was cancer (28%) followed by heart disease (13%), which are both slightly lower than the England average. Both circulatory disease (10%) and Stroke (8%) account for a slightly higher proportion of deaths than the England average with accidents (1%) and suicides (<1%) slightly lower.<sup>18</sup>

The current end of life care service provision on the Island is as follows:

Location	Service Provided
St. Mary's Hospital	The Trust provides inpatient care for people with palliative care needs.  A team of <b>clinical nurse specialists</b> provides specialist palliative care assistance and advice about end of life care to clinicians while a nominated nurse lead will develop services for people at the end of life.  <b>Hours covered:</b> 08.30–16.30 seven days a week.
	A <b>consultant clinical and health psychologist</b> works full time across Oncology and Specialist Palliative Care, covering the hospital and hospice, based with the Hospital Palliative Care Team two days a week.
	Two full-time <b>consultants in palliative medicine</b> , based at the hospice, are shared with and employed by the IOW NHS Trust.  <b>Hours covered:</b> 08.30–16.30 Monday to Friday.
	<b>Occupational Therapy</b> , provided by 1.0 WTE Occupational Therapist and 0.67 WTE Occupational Therapy Assistant, facilitates early and appropriate discharge for people with a palliative diagnosis.  <b>Hours covered:</b> 09.00–17.00 Monday to Friday.
Primary Care (GPs)	<b>Patient Care</b>  The GPs work with community nursing and the Earl Mountbatten Hospice Community Team. GPs keep a record of end of life patients on their own clinical systems, provide data for the electronic palliative care record and generate prescriptions for 'just in case' drugs. They can initiate triage bypass cards.
	<b>Support Services</b>  Primary care provides advice and support to patients and families in their own homes and at surgeries, coordinates and refers patients to secondary care services. They talk to patients, relatives and carers about available options and document their decisions. GPs complete the relevant forms for patients and their families to access financial support, and can provide support to families and carers post bereavement.  <b>Hours covered:</b> 24/7

Location	Service Provided
<p><b>Earl Mountbatten Hospice (EMH)</b></p>	<p>The <b>Earl Mountbatten Hospice (EMH)</b> provides inpatient, outpatient, community and supportive care (including physiotherapy, occupational therapy, lymphoedema services, complementary and creative therapies, psychological and spiritual support, including bereavement support for adults, families and children). The hospice has integrated the community nursing teams to deliver palliative care in the community (see below) and has recently recruited two consultants in palliative medicine (referenced above), shared with and employed by the IOW NHS Trust, which has significantly improved communication across all services.</p> <p><b>Hours covered:</b> 24/7</p> <p>The <b>EMH John Cheverton Centre</b> at EMH provides information, self-help, rehabilitation and day services for people with any life limiting condition living on the Island. Some will have been assessed by clinical nurse specialists and referred for specialist care at home services, whilst others can self-refer and drop in as required. There are a full range of services available, including: nursing &amp; medical clinics and support, a rehabilitation gym, occupational therapy, physiotherapy, lymphoedema services, complementary and creative therapies, psychological services including bereavement support and Chaplaincy and spiritual care. The centre also provides an information and support service to adults and children who are living with or who are curious about end of life issues.</p> <p>A large group of volunteers are available to support users of the centre through offering hospitality and social support, signposting, accessing information, etc.</p> <p>The centre is open to the public with the aim of changing public perceptions of end of life care and offers regular community events open to all, such as a concert series, art exhibitions, death café etc. It is also used as a venue by a number of related groups across the Island such as MNDA, Alzheimer's UK, etc.</p> <p><b>Hours covered:</b> seven days per week – Please see website.</p>
<p><b>IOW Council Social Care</b></p>	<p>The Isle of Wight Council will work with appropriate partners to develop care and support such as housing and benefits. They will integrate activity in areas where there is evidence that effective integration of services materially improves people's well-being e.g. end of life care. This will stop people reaching crisis and reduce emergency admissions to hospitals. The Isle of Wight Council can arrange pre-bereavement support for carers who have a family member or cared for person at end of life.</p> <p>The Care Act, introduced in April 2015, includes new legislation and guidance around the Care and Support (Eligibility Criteria) Regulations 2014. The eligibility framework will ensure there is clarity and consistency around the Isle of Wight Council determinations on eligibility for all service users and carers who are all entitled to an assessment of their needs.</p> <p>Carers can be eligible for support in their own right. The national eligibility threshold for carers is based on the impact of the carer's needs and the support it has on their well-being. The Isle of Wight Council can carry out a Carer's Assessment to identify any needs, identify how they can improve and maintain their well-being and any outcomes the person wishes to achieve in their day-to-day life.</p> <p>Fast track applies across whole range of services, not just residential and social care.</p> <p><b>Hours covered:</b> 09.00–17.00 Monday to Thursday, 09.00–16.30 Friday Out of hours for urgent contact</p>

Location	Service Provided
<b>Residential care</b>	<p>For <b>residential care</b>, there is a fast-track process for people nearing the end of life who require continuing health care. Agencies providing a sitting service are asked to respond within an hour and a half with care being arranged within 24 hours.</p> <p><b>Hours covered:</b> 24/7</p>
<b>Own Home / Community</b>	<p>The <b>Community Nursing (CN) Service</b> for the Isle of Wight provides end of life care from all causes to people at home. The CN service works with the Earl Mountbatten Hospice Community Team to deliver care for those at the end of life in the community.</p> <p><b>Hours covered:</b> 24/7</p>
	<p>The Earl Mountbatten Hospice Community Team supports people with any life-limiting illness in the last year of life, undertaking pain and symptom control with support from the medical consultants. The team consists of nurses, nurse specialists and healthcare assistants, with an Earl Mountbatten Nursing service to cover a night shift at home, or daytime respite for carers. There is also a volunteer service to support socially isolated people. Other procedures (such as blood transfusions) are being considered for administration in the community to enable people to stay longer in their own home.</p> <p><b>Hours covered:</b> 07.30–21.30 seven days a week (The Earl Mountbatten Nursing Service offers support 24/7)</p>
	<p>The <b>Crisis Response Service</b> is a multi-disciplinary team consisting of health and social care professionals who provide up to 72 hours of care and support, 7 days a week, to enable an individual to remain at home if they wish. Targeted at people over the age of 65, the team undertakes a holistic assessment of the person, environment and support available in order to address the current crisis and to prevent future crisis by putting mitigation plans in place, including signposting to relevant services as needed for further care and support. The Crisis Response Service will be scoping out service developments in year. The service is co-ordinated through the 111/single point of access system at the hub and provides crisis care for 72 hours, after which the person is handed over to other services.</p> <p><b>Hours covered:</b> 08.30–16.30 seven days a week</p>
	<p><b>Anticipatory Prescribing ('Just in Case' boxes):</b> Out-of-hours access to medication that might be required by a person nearing the end of life has been facilitated by the introduction of "Just-in-case" boxes, which include a set-stock of palliative drugs that can be utilised by an out-of-hours doctor. The information on the drugs necessary for palliative care is located on GP systems for ease of reference.</p> <p><b>Hours covered:</b> 24/7</p>

Location	Service Provided
<b>Carers</b>	<p>Carers IW are the jointly commissioned service that provide information, advice and dedicated support to carers and former carers living on the Isle of Wight, they provide a range of services offering the carer the opportunity to meet with others who understand the pressures experienced by their caring responsibilities and offer ways to support them to continue with their caring role.</p> <p>The services they provide allow the carer to have a break away from their caring responsibilities and participate in various activities held across the island, including the opportunity to attend a carer's respite weekend.</p> <p>Carers IW offer a large range of support for the carer including one to one emotional support, moving people safely training, wellbeing courses, moving on courses for carers who find themselves no longer caring and advocacy.</p> <p><b>Hours covered:</b> 09.00–17.00 Monday to Friday.</p>
<b>Chaplaincy</b>	<p>It is recognised that all people have spiritual life which is especially important when providing holistic care to patients and their families in hospital, in the hospice or in the home. Chaplaincy is available to all people of faith or no faith, be they patients, family members, carers or staff members; there are links to all faith groups as and when they may be needed.</p> <p><b>Chaplaincy at St Mary's</b> is available 24/7 with a Chaplain in the hospital during the day and on call at the end of the working day and at the weekend, especially available for End of Life Care, not solely for religious needs, but for anyone who would like or needs support. There is a Chapel and multi-faith room on-site which provides a quiet space in the midst of the noise of the hospital ward.</p> <p><b>Chaplaincy at Earl Mountbatten Hospice</b> is available during the day from either the duty Chaplain or one of our volunteers, providing support and a listening ear for those with a range of religious and spiritual needs. As part of our support to the bereaved, a memorial service is held at the Hospice for those who have recently lost a loved one.</p> <p><b>Hours Covered:</b> 24/7</p>
<b>H.M. Prison, Isle of Wight</b>	<p>Services are commissioned by NHS England (Health and Justice Thames Valley Area Team). Within HMP Isle of Wight, Care UK provides inpatient facilities that include 2 Kings Fund bedrooms adapted to meet the needs of people with palliative care needs or requiring end of life care. Services are GP-led, supported by nursing and allied health professionals in the inpatient and outpatient settings. Chaplaincy and pastoral care are provided by HMP Isle of Wight.</p> <p><b>Hours Covered:</b> 24/7</p>

### Coordination of care across different settings

The multi-agency management of people requiring end of life care is located in the Urgent Care Communication 'hub' that facilitates the response of the 111 service and allows access to the Advance Care Plan (ACP). The ACP records are placed electronically on the Adastra information system held at the hub so that it is clear that healthcare professionals have had discussions about end of life care with individuals and their carers. The EMH/Macmillan Specialist Care at Home team is accessed via the Hospice.

### Information and support for individuals and their carers

The Island's voluntary services for cancer support have worked with the statutory services during 2014/15 to develop a comprehensive directory of available support; this will be made public in April 2015. The John Cheverton Centre also provides information and support for adults, families and children living with or curious about death, dying and bereavement. The Isle Help Hub in Newport is the main information service for Island residents, bringing together a wide range of information and advice under one roof.

On the Isle of Wight there are currently different elements of a pathway for the management of people nearing the end of life, depending on setting:

**In the hospital setting** the Amber Care Bundle (ACB), a multi-disciplinary tool to support staff in identifying and managing people whose recovery is uncertain and may be at risk of dying in the next one or two months, is used. The ACB involves the following sequential steps: assessment, management, best practice, engagement and recovery uncertain, to ensure that people receive the appropriate management.

Benefits of the ACB include:

- Improved decision making.
- A positive impact on the multi-professional team, improving communication and MDT working.
- An increase in the confidence of nurses about when to approach medical colleagues to discuss treatment plans.
- People treated with greater dignity and respect.
- Greater clarity around preferences and plans about how these can be met.
- Lower emergency admission rates.

**In the community** the Advance Care Plan (ACP) is offered to people who are approaching end of life and aims to help with discussing and recording their preferences and wishes for end of life care. All Island practices have been commissioned by the CCG Primary Care commissioning team to deliver the ACP service.

In 2013/14, 687 new ACPs were issued across the Island's GP practices, exceeding the target of 40% of the 1% practice population estimated to die within 12 months. In the first three quarters of 2014/15, 659 new ACPs were issued, with GP Practices on track to achieve the target of 60% of the 1% practice population estimated to die within 12 months for the year.

The ACP is used for those people with cancer or long-term conditions who are nearing end of life. Further embedding within primary care to ensure that all people requiring support at the end of life are offered an ACP is continuing.

Work is currently underway to link the ACP in the community and the ACB in the hospital setting, which will enable the ACP to be centrally held, accessible by those in the hospital and the community.

## Paediatric Services

The Community outreach paediatric services provides care to children diagnosed with life-limiting, life-threatening illness and end of life palliative care.

The IOW NHS Trust provides children's hospice at home care in accordance with the 'ACT Integrated Multi-agency Care Pathway for Palliative Care for Children 2004'. This pathway has been agreed as the most appropriate model of NHS paediatric palliative care delivery.

The service is accessible via the community nursing team following a continuing care assessment and service need identified. The team work jointly with the paediatric acute team and Earl Mountbatten Hospice to provide a choice of preferred place of death for individuals. Earl Mountbatten Hospice offers a bespoke and flexible service to support dying children and their families in partnership with the paediatric palliative care team. The service offers the possibility for the child to die at the hospice under the support of the IOW NHS Trust paediatric team. Rooms can also be utilised to enable grieving families to bring the dead child to the hospice in order to spend time with the child's body prior to the child being transferred to the funeral directors.

The YMCA are commissioned to provide family-centred psychological counselling and support to promote the emotional well-being of children, young people and their families who have life-limiting and life threatening conditions. Referral is via the community children's nursing team with whom they work closely.

Children and young people also have access to a bereavement service provided by the YMCA independent provider. This provision is for all children and young people who have experienced bereavement. EMH can also offer bereavement support to families and children.

NICE guidance for 'End of Life Care for Infants, Children and Young People' is due for publication in 2016. This document is likely to specify specialist psychological support that addresses the psychological well-being of children and their families.

There is a Memorandum of Understanding between the NHS Trust and EMH for children and young people in the latter stages of end of life to be in a preferred place of death. Rooms are made available in the hospice with NHS staff (paediatric team) delivering the care. The Hospice also provides after-death care.

Work is being undertaken with the hospice to extend the services that are offered to children and young people on the Isle of Wight. The CCG and NHS Trust paediatric service work closely with 'Together for Short Lives' to further develop the Island's paediatric end of life services in line with national best practice.

**“Sometimes I feel like I’m the last leaf on a tree”.**

**Quote from a man living alone, with little community support to help him deal with Cancer – an extraordinary metaphor implying loneliness in dealing with cancer and a sense of trying to hang on against the odds. This man attended a befriending session, where he was able to talk to someone who had experience of dealing with cancer themselves, who empathetically understood where he was coming from.**

**He no longer felt so isolated.**

**Provided by the chairman of a cancer support network based on the Isle of Wight.**



## 2.2 Service Performance

Since 2009 the proportion of deaths occurring in hospital has fallen (see Figure 4, below). Deaths in the hospice and nursing/residential homes have shown an increase, while deaths in the home have remained broadly the same.

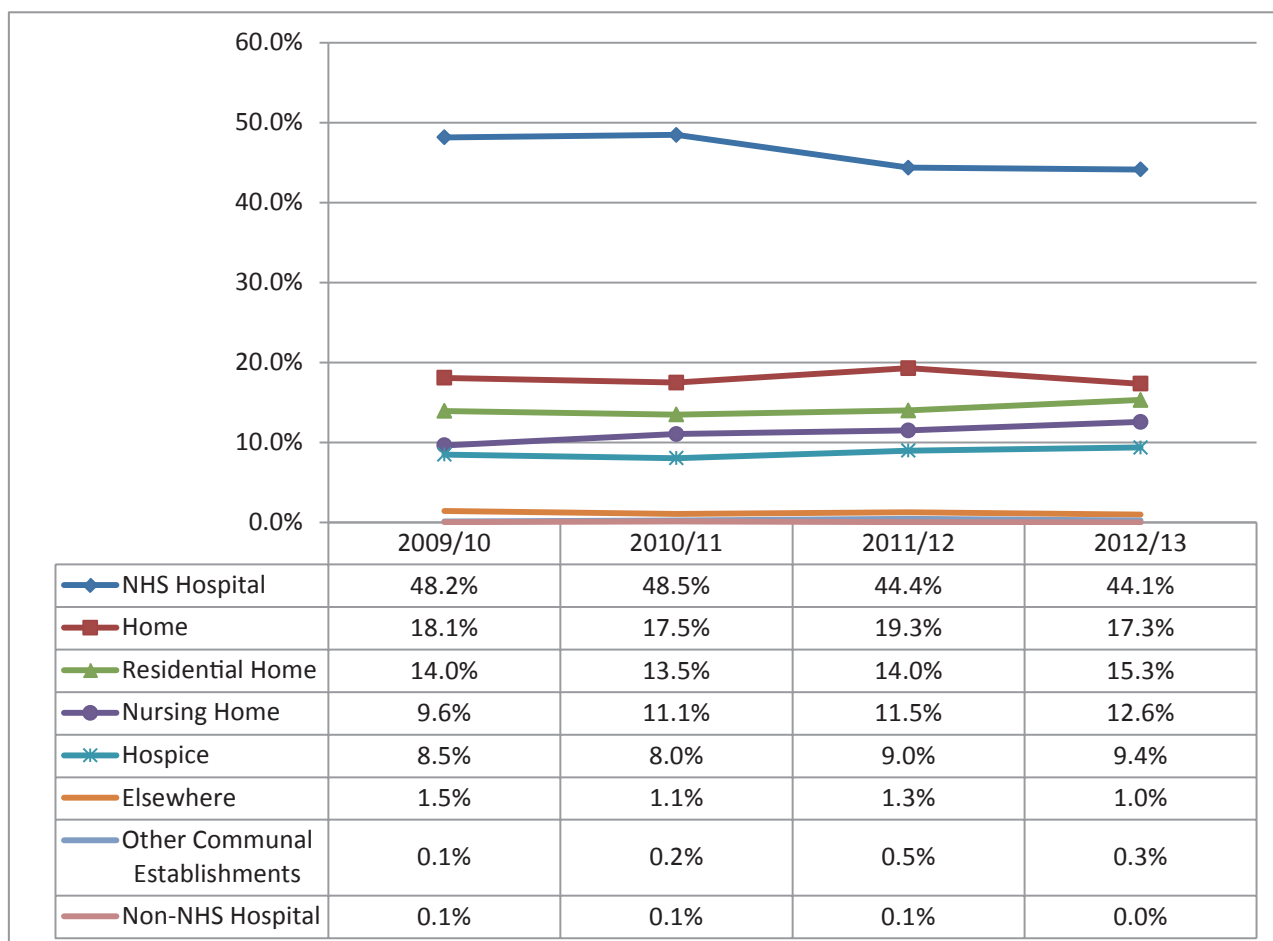


Figure 4 Comparison of Place of Death on the Isle of Wight 2009–2013, Source: IOW CCG Performance Report

The End of Life Care CCG profile, launched in April 2014, draws together a wide range of information concerning all deaths in England registered between 2010 and 2012 inclusive, providing an overview of variations in cause and place of death by age and sex for each CCG.

Table 1 and Figure 5 Place and cause of deaths registered for Isle of Wight CCG 2010–2012 inclusive', demonstrate that the Isle of Wight CCG performs better against the national average for England in terms of numbers of deaths in hospital, with a higher proportion of deaths outside hospital taking place in care homes or hospices rather than at home.

Isle of Wight CCG			England Average	Benchmark against England
Indicator	No. Deaths	Proportion		
Deaths in Hospital (Persons – All Ages)	767	45.27	50.71	Lower
Deaths in Home (Persons – All Ages)	317	18.74	21.54	Lower
Deaths in Care Home (Persons – All Ages)	434	25.61	19.59	Higher
Deaths in Hospice (Persons – All Ages)	144	8.48	5.59	Higher
<b>By Cause</b>				
Cancer (Persons, All Ages)	457	26.98	28.51	Lower
Cardiovascular (Persons, All Ages)	483	28.7	27.03	Higher
Respiratory (Persons, All Ages)	207	12.22	13.91	Lower
Other (Persons, All Ages)	542	32.02	30.1	Higher

Table 1 Place and cause of deaths registered for Isle of Wight CCG 2010–2012 inclusive.

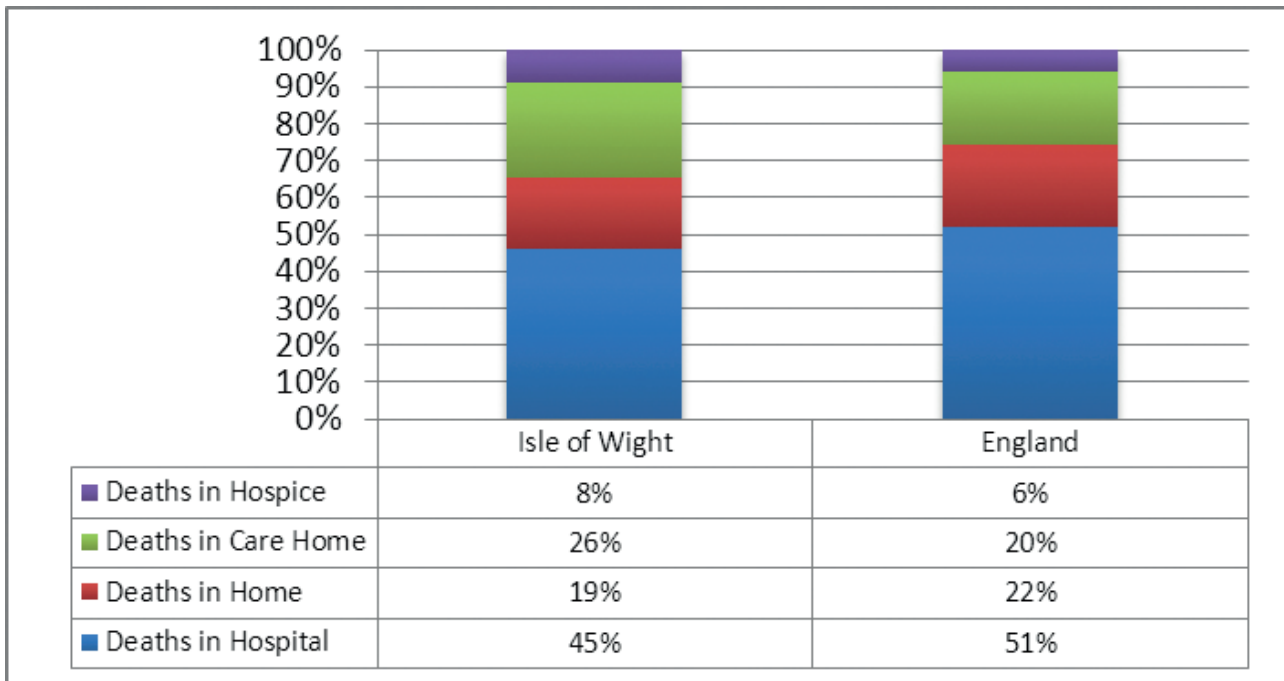


Figure 5 Place and cause of deaths registered for Isle of Wight CCG 2010–2012 inclusive

Figure 6 shows outcomes from the National Survey of Bereaved People (VOICES) 2011–2012<sup>19</sup> which demonstrates that the Isle of Wight performs above the national average in overall quality of care, but below the national average for dignity and respect and involvement in decision making.

National Survey of Bereaved People (VOICES) 2011–2012 ONS	IOW	England
	Weighted Percentage	
<b>Overall quality of care</b>		
Q51. Overall, and taking all services into account, how would you rate his/her care in the last three months of life?		
Outstanding/Excellent	45.8	43.2
Q14. Overall, do you feel that the care he/she got from the district and community nurses in the last three months was excellent?		
Excellent	83.3	78.6
Q19. Overall, do you feel that the care he/she got from the GP in the last three months was excellent?		
Excellent	77.7	72.4
<b>Dignity and Respect</b>		
Q25a. During his/her last hospital admission, were he/she always treated with dignity and respect by Doctors?		
Always	52.4	57.9
Q25b. During their last hospital admission, were he/she always treated with dignity and respect by Nurses? <sup>1</sup>		
Always	43.4	49.9
<b>Support for carer and family</b>		
Q46. Were you or his/her family given enough help and support by the health care team at the actual time of death?		
Yes, definitely	59.9	59.8
Q47. After he/she died, did staff deal with you or his/her family in a sensitive manner?		
Yes	94.3	93.5
Q49. Looking back over the last three months of his/her life, were you involved in decisions about his/her care as much as you would have wanted?		
I was involved as much as I wanted to be	74.5	77.9

Figure 6 National Survey of Bereaved People (VOICES) 2011–2012 ONS

## Cost

A survey by the Department of Health<sup>20</sup> showed huge variance in spend on adult palliative and end of life care in 2010/11, with one PCT spending around £0.2m on specialist palliative care alone, and another around £21m. This variation means that one PCT spent approximately £186 per death on specialist palliative care, while another spent £6,213. A total of 61% of all PCTs spent less than £1,000 per death in their PCT.

- On the IOW, total spend on end of life care per death was £1,254 in 2010/11 against a national average of £1,096 per death.<sup>21</sup>

As part of the implementation plan following publication of this strategy, a full review of the cost and funding of end of life care on the Island needs to be undertaken to inform future commissioning intentions.

### 2.3 Service Gaps

The independent review conducted in early 2014, the CQC report in June 2014 and the End of Life Care Strategy Workshop in November 2014, highlighted the following gaps in end of life care provision on the Island:

- Lack of resources – workforce, infrastructure, IT, education and training.
- The delivery of end of life care is fragmented, with the use of the Amber Care Bundle (ACB) in the hospital and the Gold Standards Framework (GSF) in primary care, linking to the Advanced Care Plan (ACP) on Adastra. There are also issues around implementation of the ACB, including lack of uptake in ACB education and training.
- Education and training in end of life care is inconsistent and has led to uncertainty among healthcare professionals about how to care for people at end of life and support their carers/families. A recent national RCN survey found that only 10% of nurses feel competent to deliver end of life care.
- Difficulties in accessing patient records across settings.
- The input of occupational therapy, community nursing and social care elements of end of life care need to be defined more clearly.
- Insufficient 24/7 access to vital services and information.
- Inconsistent use of documentation including inadequate recording of discussions/decisions with those at the end of life and their carers/families.
- Failure to recognise people at end of life, which can lead to inappropriate care and insufficient planning.
- Inconsistency in effective engagement of staff on end of life care, including DNACPR Policy.
- Lack of public awareness and engagement with end of life care or understanding about death.
- Insufficient audits or quality measures in place to measure effectiveness of end of life care.
- Insufficient workforce capacity across the Isle of Wight Health and Social Care economy, particularly in Community Nursing, Occupational Therapy and Home Care Support Workers:
  - » After 8.00pm there is only one community nurse on call for the whole Island to cover all community nursing needs including end of life care.

- » The Occupational Therapy service has had to prioritise discharges due to demand exceeding capacity. As a result, people that require Occupational Therapy input following discharge are referred to the IOW Council funded service that utilises Fair Access to Care criteria for prioritisation.
- » The eight agencies providing a sitting service on the Island currently lack the capacity to meet demands.
- There is national recognition that people with dementia may not receive the same services as those who do not have dementia: this includes the assessment and treatment of pain<sup>22</sup>. The Department of Health State of the Nation Report (2013)<sup>23</sup> highlighted that too many people with dementia are not supported to have early discussions and make plans for their end of life care.
- The current paediatric bereavement services, while receiving referrals from some children and young people in pre-bereavement (i.e. when they have a terminally ill/dying parent) does not currently offer services automatically to all. However, evidence exists to demonstrate that supporting people in pre-bereavement can aid coping after the death of someone close to them, and therefore further development of this service needs to be explored.
- It has also been recommended that prisons implement an end of life care plan for every prisoner diagnosed with a terminal illness<sup>24</sup>. The plan should follow the six step pathway as set out in the National End of Life Care Programme prison guide. Between 2002 and 2012, the number of sentenced prisoners aged 60 and over increased by 142 per cent from 1,376 to 3,333. As the prison population ages, the number of deaths from chronic disease or simply old age is expected to rise. There is likely to be a corresponding increase in the number of cases where prisoners would benefit from planned end of life care.
- Many people on the Island who are housed in supported living provided by a range of housing associations. As part of implementing the Island's End Of Life Care Strategy we need to ensure that all staff who look after people in all types of housing and settings need training in good end of life care, are aware of the needs and wishes of dying people, and have the confidence to have sensitive discussions with the person they are supporting and also with any family or friends who are close to them.

### 3. Where do we want to be?

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We want high-quality end of life care on the Isle of Wight to be easily accessible, available at the right place at the right time and delivered by the right people to support those at the end of their life, and their families and carers. We will work hard to ensure that people on the Island live as well as possible towards the end of their life, and have a good death in their place of choice, regardless of diagnosis.

The workshop in November 2014 brought together a wide range of stakeholders to decide on how best to reach these goals. Scoping exercises conducted at the workshop outlined the journey we needed to undertake to enable us to achieve our aspirations for end of life care on the Island.

The first step in this journey has been the development of this strategy, including an implementation plan (Section 4.1) developed with broad stakeholder engagement, which includes outcomes from the November workshop. Progress is already being made in many of the areas identified in the implementation plan.

The next step will be the development of detailed action plans by stakeholder groups, as detailed in section 4.1, to keep us on the right path to ensure that we achieve our vision.

The careful monitoring of outcomes over the coming years will help us to understand if we are delivering the identified benefits and realising our ambitions for improved end of life care on the Isle of Wight.

We would like end of life care on the Island to be recognised as best practice nationally for excellent, consistent and sustainable end of life care appropriate for every individual.

#### 3.1 Outcome measures and targets

Not everything in end of life care is measurable. Whilst we will take steps to seek innovative ways of evaluating impact, we will also do our best to avoid doing only what is measurable. The impact of some of these actions is likely to be incremental and occur over a longer period of time. People who are living with progressive, life-limiting conditions must be at the centre of any decision, plan or action for their care or treatment.

Suggested measures include<sup>25</sup>:

- Quality accountability report – key outcome measures, individual/carer feedback of experience of care and accreditation of organisations
  - » VOICES, local feedback
  - » Accreditation.
- Right person – people who are approaching the end of life are recognised early
  - » Number of identified people on register/total number of deaths
  - » Number of carers offered assessment and care in bereavement
  - » Number of people on the register with non-cancer diagnosis (equity of access).
- Right care – people whose care planning has been recorded and care tailored to meet needs
  - » Number of people offered ACP discussions/numbers on register
  - » Process in place for carer feedback following death, to assess care aligned to preferences, e.g. bereaved carer's views on the quality of care in the last 3 months of life.
- Right place – people enabled to live and die where they choose
  - » Number of people who die in usual place of residence and preferred place of choice/number on register
  - » Hospitalisation rates, length of stay, rates of emergency admissions, etc.
- Right time – people who receive timely, proactive anticipatory care, including in the final days
  - » Numbers of people for whom anticipatory care plan was used
  - » Care plan for final days in place.
- Every time – consistency of care delivery; workforce trained and enabled; family and carers supported
  - » Evidence of consistency and sustainability of individual outcomes, e.g. regular audit feedback or monitoring, embedding in policy and protocols or external accreditation
  - » Evidence that workforce is trained and enabled
  - » Family and carers feeling supported.

Other local measures for development may include:

- Pain scores.
- Percentage of compliments, complaints, incidents and SIRIs relating to EOLC in primary care, secondary care and the third sector.
- Hospice-specific measures, particularly day care and community involvement.
- Programmes for children and the dying.
- Readmissions to providers.

We will work to enhance health and care professionals' understanding of data and intelligence to develop robust systems to assess need and monitor service delivery. The data and Public Health input will also help provide the evidence to identify inequalities and gaps in provision as well as developing service improvements. Public Health can support the development of tools to gain an understanding of the experience of people, carers and their families.

### 3.2 Benefits

- The quality of end of life care provision will be improved.
- The individual, carers and family should feel well supported and appropriately involved in their care planning.
- The individual should be able to die in their place of choice with pain and other symptoms effectively managed.
- The individual, carers and family should feel confident in the skills and knowledge of their health and social care professionals.
- The individual, carers and family should know who to contact in an emergency.
- All staff should feel confident in their skills and knowledge in how to recognise, support and care for an individual at the end of life, and their carers and family.
- Better communication between professionals and organisations across the public, private and third sector, facilitated by improved systems and resources.
- End of life care provision should become more cost effective across the Island's health and social care economy as more people are cared for in the community.



### 3.3 Stakeholder engagement

It is essential that the views and health needs of the Island population and stakeholder organisations are reflected in the strategy. Key stakeholders have been fully engaged in the development of the IOW EOLC Strategy, with representatives from all stakeholder groups interviewed during the 2014 EOLC review and invited to attend the EOLC workshop in November 2014. Key stakeholders will continue to be engaged throughout all phases of strategy implementation.

A full list of stakeholders can be found in Appendix 6. Key stakeholders include:

- Earl Mountbatten Hospice
- Isle of Wight NHS Trust (acute and community services)
- General Practice
- Isle of Wight Clinical Commissioning Group
- Service Users and Carers
- Isle of Wight Council Social Care
- Nursing Homes
- Residential Homes
- Voluntary sector
- National End of Life Care Programme
- NHSE/Prisons.

We will work with the Isle of Wight Public Health team to increase public awareness around end of life care.

“I now realise that having choice and control in life and death is equally important”.<sup>26</sup>

## 4. How do we get there?

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- Review end of life care on the Island against the LACDP five priority areas and consider how we will deliver each of them for individuals and those important to them.
- Ensure that the EOLC Ambitions Partnership's six ambitions for end of life care are fully embedded in the current and future delivery of end of life care on the Island.
- Develop holistic and co-ordinated Island-wide end of life care offering a 'menu of choice' – an individualised journey within one integrated system of care across the whole health and social care economy.
- Increase public awareness around end of life, encouraging culture change to enable good conversations to take place and ensure accessibility of information to allow informed planning.
- Train, support and empower staff, give them the confidence to identify and care for those at the end of their lives, and the tools to communicate clearly and sensitively with individuals, their carers/families, including them in any decisions about their care. Embed this training as mandatory for all staff, committing organisational priority and resources.
- Implement the necessary systems to enable rapid, 24/7 access to end of life care with the right resources in the right place, allowing those at the end of their life to die in their place of choice and to ensure that they and their carers/families are fully supported in that choice. To be aligned with NHS England's proposals to ensure that there is meaningful choice and control over services offered in end of life care, due to be released in the Autumn of 2015.
- Improve identification of those at the end of life: ensure that staff in all settings have the training, support and tools to undertake 'opportunistic assessment' to better recognise and identify those at end of life and communicate this appropriately to other health and social care professionals.
- Develop one Care Plan – agreed with the person and their carers/families – a shared, person-held record: regularly reviewed, easily updated, easily accessed and visible to all who need to see it.
- Assign a dedicated keyworker to each person, to coordinate and review their care across all services in all settings and develop fast track processes to access continuing care for those nearing the end of life.

- Link the End of Life Care Strategy with other initiatives such as My Life, A Full Life and the needs of people with dementia.
- Work with Public Health to increase public awareness around end of life and to enhance health and care professionals' understanding and use of data and intelligence to develop robust systems to monitor and assess and understand people's experience in order to improve services and identify inequalities and gaps in provision.
- Improve the commissioning of palliative and end of life care services so that people living with progressive, life-limiting conditions, and those close to them, can receive the best possible care which matches their level of need and, as far as possible, preference.
- Improve performance management and governance systems to effectively monitor outcomes, evaluate service change and inform future understanding of end of life care provision on the Island.
- Ensure that end of life care on the Island meets the needs of all people at the end of life.
- Embed end of life care as everyday practice – make it everyone's business.

#### 4.1 Implementation Plan

The End of Life Care Strategy implementation plan has been developed through broad stakeholder engagement, including the scoping exercises and outcomes from the workshop held in November 2014.

It was agreed at the workshop that the Island's end of life steering groups be tasked with working together to produce detailed action plans, informed by the implementation plan (below) and with reference to the latest national guidance, such as the forthcoming End of Life Ambitions Partnership 'Shared Vision for Better Care 2015–2020', and the new NICE Guidelines on Care of the Dying Adult which are in consultation and development in the Summer/Autumn of 2015. The public will be fully engaged and consulted in the development of the action plans. The action plans will be finalised by the end of October 2015 and progress against them will be formally monitored by the IOW CCG, the IOW NHS Trust and EMH.

An IT task force will also need to be set up to review the sharing and accessibility of patient records including care plans, and to develop an action plan to address any issues.

The end of life care action plans will be used to deliver the Isle of Wight's End of Life Care Strategy, supported as necessary by the CCG and third sector organisations, to achieve our vision for end of life care on the Isle of Wight and ensure that people on the Island live as well as possible towards the end of their life, and have a good death in their place of choice.

Due to the high levels of engagement and enthusiasm for positive change in end of life care, significant progress has already been made in many areas outlined during the workshop in November 2014 and included in the following implementation plan, including:

- Individualised care plans have been developed (Appendix 7).
- IOW NHS Trust End of Life Care Policy has been developed (Appendix 8).
- A Memorandum of Understanding between EMH and IOW NHS Trust has been signed regarding the practical arrangements for children who are assessed as suitable for admission to the hospice bed, under the care of the paediatric palliative care team (Appendix 9).
- Work is underway to enable the individualised advanced care plan to be held centrally, visible to all.
- Systematic gathering of feedback from carers or relatives of those who die at St. Mary's Hospital has begun to inform and improve standards of care.
- Implementing training and encouraging leadership and support.
- Weekly Cancer befriending service meetings are now taking place in the Oncology Unit at St Mary's to provide a friendly ear while people are waiting for clinical appointments as well as an opportunity for ongoing 1:1 contact.
- The Island's EOL Steering group is considering the draft NICE guidelines on Care of the Dying Adult and will provide feedback to the national stakeholder consultation.
- A bid has been submitted for an EOL Facilitator to work alongside the palliative care team.
- **End Of Life Champions**  
There are now End of Life Champions in most of the clinical areas, two training courses have already been delivered, and further training is scheduled. The response to the training days has been very positive and there have been reported changes in practice identifying that patient's wishes were listened to and acted on. All the Champions have been contacted recently to support the roll out of the Priorities for Care Nursing Care Plan to support their colleagues in using the care plan effectively.
- **24/7 Working**  
Palliative and End of Life Care is provided seven days a week during the 9 to 5 working hours period. Support for those at the end of their life is provided by Earl Mountbatten Hospice through telephone contact. Families, carers and healthcare professionals are able to access support and advice by phoning the ward at Earl Mountbatten Hospice, and in exceptional circumstances the Consultants in Palliative Medicine will be contacted to provide advice in complex situations.

The Community Nursing Team has implemented a rostered 'on-call' out of hours service, where a nurse is available to provide care and support if a visit is necessary. This service is further supported by a Senior Nurse who is available to provide information support and advice to the visiting nurse. This has significantly improved the available service for End of Life Care.

Developing the skills of Ambulance Staff has also been explored so that if possible, the needs of an individual can be addressed without bringing them to hospital. This service involves the development of skills, knowledge and flexible management of clinical situations to meet the needs of individuals.

### Implementation Plan

#### Service And Workforce Review

Workforce review to analyse skill mix and capacity across all services and develop overarching action plan to address service and workforce issues and ensure 24/7 access to end of life care.

- Review out of hours (OOHs) provision across health and social care economy.
- Review Community Nursing service and address gaps in OOHs provision.
- Review and develop Occupational Therapy service.
- When developing or reviewing service specifications ensure that end of life care is embedded into contracts.
- Improve performance management and governance systems with effective monitoring and evaluation of outcomes.
- Ensure the expected outcomes from the strategy are aligned with the commissioning and delivery of care within HMP Isle of Wight
- Scope potential for setting up '*Community Interest Company*' Carers agency to address shortage of carers.
- Scope potential for enhancing crisis response, e.g. better utilisation of paramedics in EOLC.
- Review and develop 'key worker' for those at end of life.
- Scope potential for developing further outreach services to help reduce admissions.
- Review paediatric services.
- Review access to pharmacy, diagnostics and assistive technology.
- Acknowledge and find ways to mitigate high turnover of staff.

#### Communication & Engagement

Engage EMH, Public Health, MLAF, Isle Help, and Dying Matters to develop an action plan to:

- Increase public awareness and culture change around end of life matters.
- Engage more volunteers in EOL care.
- Improve signposting to relevant advice, information and support.
- Encourage greater communication between and within teams and organisations.

### Implementation Plan

#### Education & Training

Review end of life care education and training on the Isle of Wight for health and social care professionals, individuals and their families and carers. Develop action plan to:

- Identify, communicate and publicise all available training.
- Implement additional training where necessary.
- Agree minimum competency levels across all sectors and embed in mandatory training, committing organisational prioritisation and resource to ensure uptake and embed end of life care as everyday practice.
- Encourage leadership and support with modelling of good behaviour.
- Implement systems to support and empower staff to become confident in communicating with and caring for those at the end of life, and their families.
- Educate, support and empower individuals and their families/carers to have more control, linking with Public Health, MLAFL and Dying Matters.

#### Development Of Individualised Journey And Care Plan

Develop detailed action plan to progress the following:

- Develop and agree an individualised care plan, ensuring regular reviews and updates are embedded in systems.
- Develop an individualised end of life journey for the Island – one system of coordinated care across the Island's health and social care sector, offering a 'menu of choice' for the individual.
- Improve methods and tools for identification of those at end of life.
- Consider implementing 'green sleeve' person-held record in short term.
- Develop and implement tools to support planning and to allow better conversations between individuals and professionals.
- Review admission avoidance, direct admission, enhanced discharge and fast track continuing care.

#### Sharing Of Patient Record – IT Taskforce

Set up IT taskforce to address integration and information sharing across the Island's health and social care economy, developing detailed action plan to:

- Develop systems to allow one easily updated patient record, one care plan and one system accessible by all.
- Flag individuals at EOL on IT systems to enable awareness and access to care plan.
- Implement systems to facilitate person-held record.

#### Resources

Develop action plan to review resources across the whole Island economy.

**“How people die  
remains in the  
memory of those  
who live on”.**

**Dame Cicely Saunders (1918–2005) founder of the  
modern hospice movement**



## Further Information

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For further information about End of Life Care please see the following:

### NHS Choices: End Of Life Care

**This guide is for people who are approaching the end of their life. Some parts of it may also be useful for people who are caring for someone who is dying, or people who want to plan in advance for their end of life care.**

It explains what you can expect from end of life care, including palliative care to control pain and other symptoms and to offer psychological, social and spiritual support.

You can also find information about your rights and choices, including refusing treatment, setting down your wishes for your future treatment, and how to give someone the legal right to make decisions for you if you are no longer capable.

This guide also contains information about talking to your family and carers about dying and about your wishes.

Website: <http://www.nhs.uk/planners/end-of-life-care/Pages/End-of-life-care.aspx>

### Earl Mountbatten Hospice

Website: [www.iwhospice.org](http://www.iwhospice.org)

Tel: 01983 529 511

### Dying Matters

Website: <http://www.dyingmatters.org>

### Macmillan

Website: <http://www.macmillan.org.uk>

Tel: 0808 808 0000

### Marie Curie

Website: [www.mariecurie.org.uk](http://www.mariecurie.org.uk)

Tel: 0800 090 2309

### Cruse Bereavement

Website: [www.cruse.org.uk](http://www.cruse.org.uk)

Tel: 01983 523 030

### Isle of Wight Cruse

Email: [isleofwight@cruse.org.uk](mailto:isleofwight@cruse.org.uk)

Tel: 01983 523 030

### AGE UK

Website: [www.ageuk.org.uk/isleofwight](http://www.ageuk.org.uk/isleofwight)

Tel: 01983 525 282

**Citizen's Advice**Website: <http://www.citizensadvice.org.uk/iwcab>

Tel: 03444 111 444

**Carers UK**

Tel: 0808 808 7777

**IW Carers – Range of support groups available locally**Email: [info@carersiw.org.uk](mailto:info@carersiw.org.uk)

Tel: 01983 533 173

**One Wight Health**Website: <http://onewighthealth.co.uk>**IW council directory to support groups**Website: <https://www.iwight.com>**YMCA Children's Bereavement Service**Website: <http://www.ymca-fg.org/for-young-people/isle-of-wight/>**Hope Again (Support for children after loss)**Website: <http://hopeagain.org.uk>**Isle of Wight End Of Life Care – Carewatch**

Tel: 0808 2780702

**Community Action IW – (Range of support to the unpaid adult carers of adults)**

Tel: 01983 524058

**The Bereavement Centre – Coffee, Care and Cake – Lake, Isle of Wight**Website: <http://www.bereavementsupportgroups.co.uk>

Tel: 07834 449069

Also see film 'Dying to Know' commissioned by Dying Matters in collaboration with Earl Mountbatten Hospice and Red Tie Theatre on the Isle of Wight. Available on the Dying Matters website at: <http://www.dyingmatters.org/page/dying-matters-films>

**Isle of Wight  
End of Life Care Strategy  
2015–2020**

**Appendices**

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## Appendix 1

## Resources

Quality Standards Programme for End of Life Care for Adults reviewed 2013	NICE	2011
More Care, Less Pathway	Independent Review	2011
End of Life Care Strategy, Fourth Annual Report v2	DH	2012
The End of Life Care Strategy: New ambitions	NCPC	2013
Time to Choose	Macmillan	2013
Dying Healed	WISH	2013
What we know now 2013 – New information collated by the National End of Life Care Intelligence Network	PHE	2013
Transforming Care at the End of Life	Deloitte	2013
RCGP Commissioning Guidance in End of Life Care	RCGP	2013
National Survey of Bereavement – VOICES	ONS	2013
Making our Health and Care Systems fit for an Ageing Population	Kings Fund	2014
National Care of the Dying Audit of Hospitals	RCP	2014
One Chance to Get It Right	LACDP	2014
Actions for End of Life Care	NHS England	2014–16
Every Moment Counts	National Voices	2014
NHS Mandate 2015–16	NHS England	2014
NICE Draft Guidelines for the Care of the Dying Adult	NICE	2015
End of Life Ambitions Partnership Draft 'Shared Vision for Better Care 2015–2020'	EOLAP	2015
Ambitions for Palliative and End of Life Care: 'A national framework for local action 2015–2020'	EOLAP	2015

## Appendix 2

## NICE Quality Standards For End Of Life Care

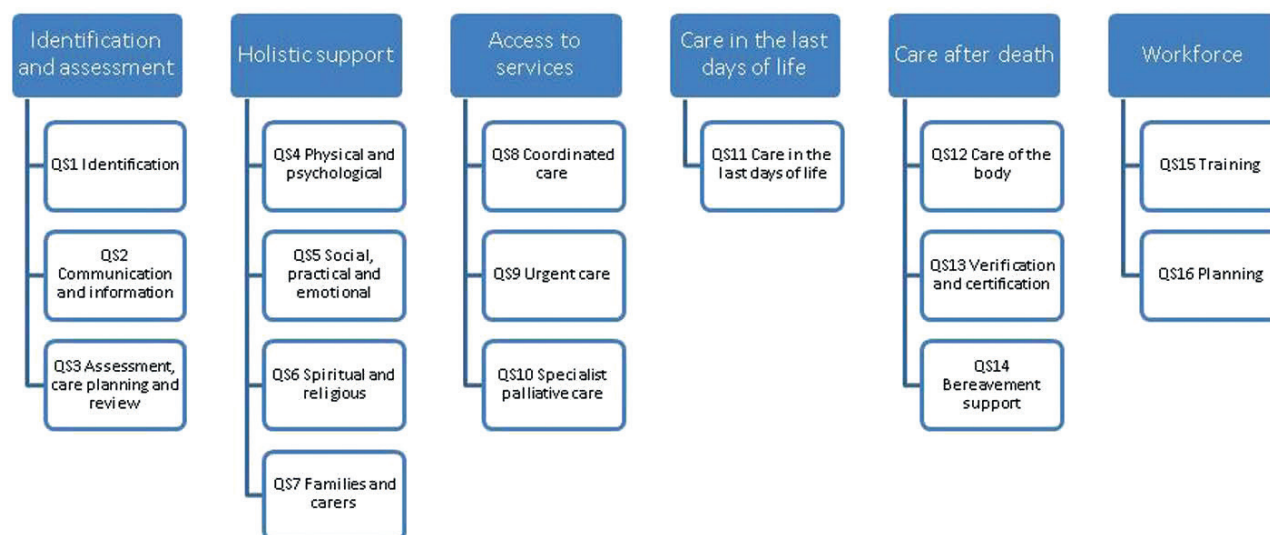


Figure 7 – NICE Quality Standards for End of Life Care for Adults – Statements

- Statement 1.** People approaching the end of life are identified in a timely way.
- Statement 2.** People approaching the end of life and their families and carers are communicated with, and offered information, in an accessible and sensitive way in response to their needs and preferences.
- Statement 3.** People approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, with the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment.
- Statement 4.** People approaching the end of life have their physical and specific psychological needs safely, effectively and appropriately met at any time of day or night, including access to medicines and equipment.
- Statement 5.** People approaching the end of life are offered timely personalised support for their social, practical and emotional needs, which is appropriate to their preferences, and maximises independence and social participation for as long as possible.

- Statement 6.** People approaching the end of life are offered spiritual and religious support appropriate to their needs and preferences.
- Statement 7.** Families and carers of people approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences.
- Statement 8.** People approaching the end of life receive consistent care that is coordinated effectively across all relevant settings and services at any time of day or night, and delivered by practitioners who are aware of the person's current medical condition, care plan and preferences.
- Statement 9.** People approaching the end of life who experience a crisis at any time of day or night receive prompt, safe and effective urgent care appropriate to their needs and preferences.
- Statement 10.** People approaching the end of life who may benefit from specialist palliative care, are offered this care in a timely way appropriate to their needs and preferences, at any time of day or night.
- Statement 11.** People in the last days of life are identified in a timely way and have their care coordinated and delivered in accordance with their personalised care plan, including rapid access to holistic support, equipment and administration of medication.
- Statement 12.** The body of a person who has died is cared for in a culturally sensitive and dignified manner.
- Statement 13.** Families and carers of people who have died receive timely verification and certification of the death.
- Statement 14.** People closely affected by a death are communicated with in a sensitive way and are offered immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences.
- Statement 15.** Health and social care workers have the knowledge, skills and attitudes necessary to be competent to provide high-quality care and support for people approaching the end of life and their families and carers.
- Statement 16.** Generalist and specialist services providing care for people approaching the end of life and their families and carers have a multidisciplinary workforce sufficient in number and skill mix to provide high-quality care and support.

## Appendix 3

## House Of End Of Life Care

NHS England and its partners are using a simple organising framework, adapted from the 'House of Care framework for people with long term conditions, to deliver person-centred, coordinated End of Life Care which helps to focus attention on the elements that need to be in place to enable high quality person-centred end of life care to be experienced. It provides a continuum from long term conditions through to end of life care.

The 'walls', 'roof', and 'foundation' of the House of Care represent four interdependent components which, if present, provide the greatest opportunity for person-centred and coordinated care (Figure 8, below). The framework assumes an active role for individuals and carers in individual care planning, working with health and social care staff, services and other support agencies.

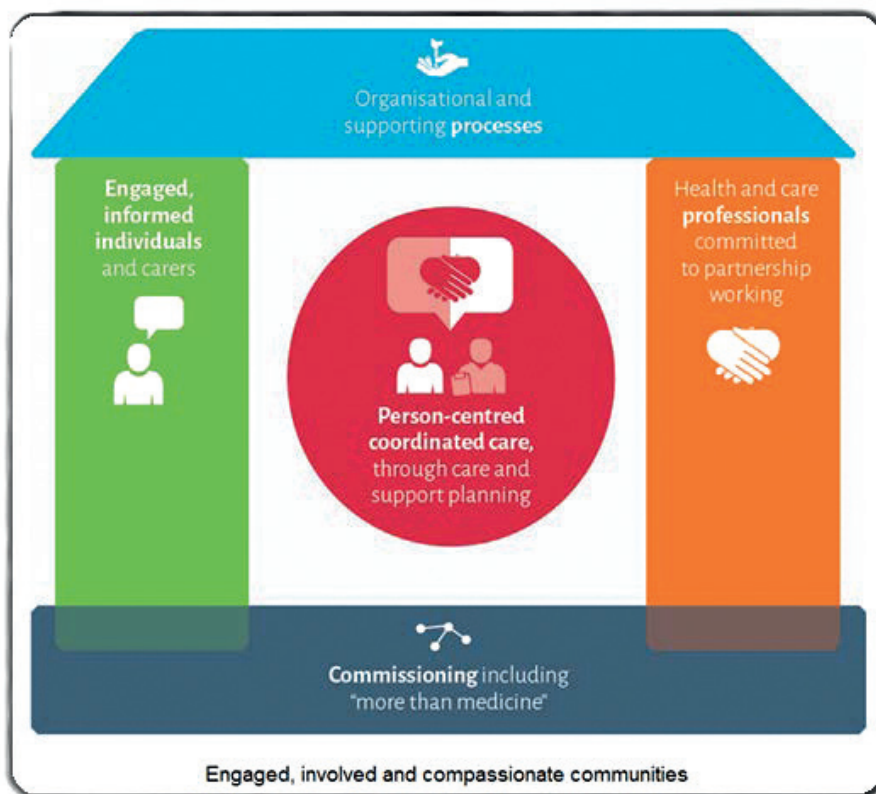


Figure 8 – End of Life House of Care Framework



## National Voices – Every Moment Counts

‘Every Moment Counts’, the narrative for ‘person-centred coordinated care’ produced for NHS England by National Voices in 2014 (Figure 9) 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.

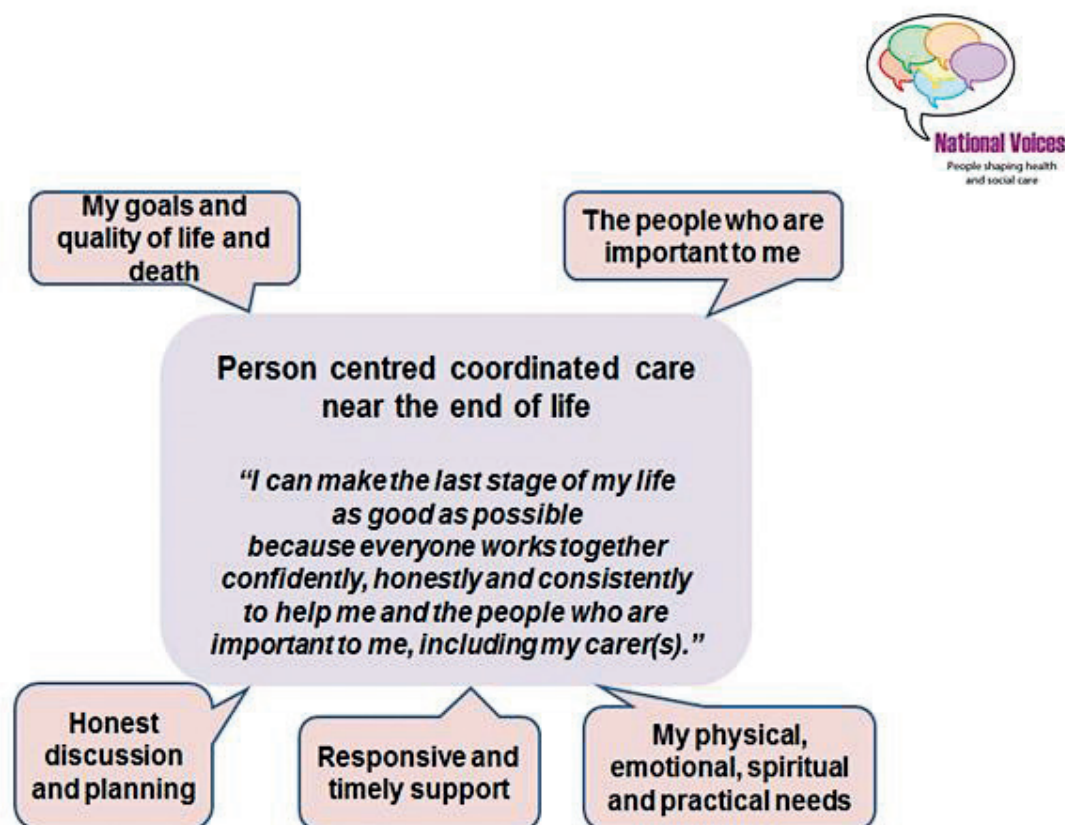


Figure 9 ‘Every Moment Counts’, the narrative for ‘person-centred coordinated care’

**End Of Life Care Review 2013/14**

**ISLE OF WIGHT  
END OF LIFE CARE REVIEW 2013/14  
REPORT**

*Thoreya Swage*

March 2014



Thoreya Swage Ltd.

PLEASE NOTE THAT THERE HAVE BEEN SIGNIFICANT CHANGES TO END OF LIFE CARE ON THE ISLE OF WIGHT SINCE THIS REVIEW WAS UNDERTAKEN IN 2013/14.

Available to view or download from:

<http://www.isleofwightccg.nhs.uk/our-priorities/end-of-life-care.htm>

If you would like a hard copy sent to you, please email: [eolc.strategy@iow.nhs.uk](mailto:eolc.strategy@iow.nhs.uk)

Or call 01983 552064 to request a copy.

## Appendix 6

## Stakeholders

Organisation	Role
Wessex Cancer Trust	Chief Executive
Earl Mountbatten Hospice	Director of Nursing Services and Education
Age UK IW	Health & Wellbeing Manager
IOW CCG	Deputy Chief Officer
IOW NHS Trust	District Nurse, Newport/Cowes Team
IOW Council	Reablement
IOW CCG	Commissioning Manager
Care Homes Association, Isle of Wight	Chair
IOW CCG	Head of Continuing Healthcare and IPC Commissioning
IOW CCG	GP – Prisons
Marie Curie	Marie Curie
IOW CCG	GP
Representing Isle of Wight Nursing Homes	Scio Health Care
Age UK IoW	Chief Officer
Southampton CCG	Lead Commissioner Palliative Care
Living Well Services	Acting Head
IOW NHS Trust	Ambulance Clinical Supervisor
IOW CCG	Commissioning Manager
Action IW	Support Group Development Officer
IOW CCG	Commissioning Manager
Earl Mountbatten Hospice	Community Nurse Manager
Earl Mountbatten Hospice	Ward Sister/Charge Nurse

Organisation	Role
IOW NHS Trust	Consultant Physician – Care of the Elderly
Care watch	Customer Relations Manager
Earl Mountbatten Hospice	Consultant
IOW NHS Trust	District Nurse Team Leader, North East Locality
Age UK	Care Navigator (Prostate Cancer)
IOW NHS Trust	Chaplain
Earl Mountbatten Hospice	Information & Support Centre Manager
Earl Mountbatten Hospice	CEO
IOW CCG	Head of Continuing Healthcare and IPC Commissioning
NHS IQ	End of Life Care
Earl Mountbatten Hospice	Clinical Psychologist
IOW NHS Trust	EoL Clinical Education Facilitator
IOW CCG	GP and Clinical Lead
Earl Mountbatten Hospice	Consultant
Marie Curie	Marie Curie
IOW CCG	GP Lead for End of Life Care
IOW Council	Commissioning Manager – Adult Social Care
Northbrook House	Nurse Manager
IOW NHS Trust	Respiratory Nurse
IOW NHS Trust	Associate Director, NHS Trust
Health Watch, Help and Care	Representative
Service User Representative	Service User Rep/Chairman with the IOW Prostate & other Urology Cancer Support Group
IOW NHS Trust	A & E Consultant, NHS Trust
IOW NHS Trust	Consultant, Diabetes/Endocrinology
IOW CCG	GP Lead for Frail Elderly and Dementia

Organisation	Role
IOW CCG	Head of Mental Health, LD and Children's Commissioning
London and South East, Marie Curie	Service Design Manager
Action IW	Health & Wellbeing Development Lead
IOW NHS Trust	Operational Manager – Clinical Lead Community Nursing
EMH	Halberry Service Development Coordinator
Penny Brohn Cancer Care	Representative
IOW CCG	Head of Quality
IOW CCG	Head of Primary Care & Corporate Business
IOW Council	Adult Social Care
IOW NHS Trust	Community Heart Failure Nurse Specialist
IOW NHS Trust	Respiratory Unit
IOW NHS Trust	Nurse Assessor, Funded Care Team
IOW NHS Trust	Deputy Head of Ambulance Service
IOW NHS Trust	Executive Medical Director
Macmillan Cancer Support	Palliative Care Nurse Specialist
IOW NHS Trust	Occupational Therapy Service Lead for acute and community services
IOW CCG	Head of Secondary Care Hospital Commissioning
IOW Council	Group Manager of Long Term Conditions Team
IOW NHS Trust	Head of Clinical Services, NHS Trust
IOW NHS Trust	Palliative Care Nurse Specialist
	Expert Advisor for End of Life Care
Service User Representative	Service User Representative
IOW CCG	GP and Chair, CCG
IOW CCG	Head of Urgent Care and Community Commissioning
MacMillan Cancer Support	Service Development Manager

Organisation	Role
IOW NHS Trust	Palliative Care Nurse Specialist
Service User Representative	Service User Representative/Facilitator for Applegate Breast Cancer Support Group
IOW NHS Trust	Executive Nurse
IOW CCG	Chief Officer
Health Watch	Manager
IOW NHS Trust	Head of Ambulance Services
IOW NHS Trust	Lead Cancer Nurse
Clinical Senate and Strategic Clinical Networks	Associate Director
Oxford University	Professor
Isle of Wight CCG Frail Older Persons Group	Service User Representative
Macmillan Cancer Support	Service Development Manager
IOW CCG	Commissioning Manager
My Life a Full Life	Programme Director

## Stakeholder And Public Engagement

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It is essential that the views and health needs of the island population and stakeholder organisations are reflected in this strategy, therefore a number of consultations were undertaken in development of this strategy.

### Phase 1: Engagement To Inform The Strategy

#### January – November 2014

- End of Life Care Review undertaken by external health consultant (see Appendix 5 of End of Life Care Strategy).
- Interviews with clinical leads and colleagues from stakeholder organisations.
- Consultation within:
  - » End of Life Steering Group
  - » Hospital End of Life Steering Group
  - » Macmillan End of Life Steering Group
- End of Life Care Strategy Workshop, 6<sup>th</sup> November 2014, attended by stakeholders and public/service user representatives.

### Phase 2: Consultation On Draft Strategy

#### Jan 2015 – August 2015

- Internal consultation with core EOLC stakeholder group.
- Stakeholder consultation with over 80 stakeholders, including third sector organisations and service user representatives.
- Considered at board level in the IOW Trust, IOW Council, EMH and IOW CCG:
  - » CCG Clinical Executive
  - » IOW NHS Trust Board
  - » Joint Adult Commissioning Board
  - » EMH Board of Trustees
- Public Consultation workshop 15<sup>th</sup> July 2015 (See Appendix B for Feedback)
- Public engagement sessions at John Cheverton Centre, EMH

- Public awareness campaign inviting public feedback on EOLC Draft Strategy (See Appendix B for Feedback), to include:
  - » Media campaign, including IWCP, Isle of Wight Radio, On the Wight, Island Echo, Facebook, Yammer, Twitter
  - » Posters circulated to GPs, Nursing, Residential and Care homes, Parish/Town Councils, Dental practices, Pharmacies, placed around hospital site.
  - » Voluntary sector emailed Strategy, briefing paper & poster – asking them to place in newsletters etc.
  - » Copies of strategy and A3 posters sent to all libraries
  - » Circulation by email
  - » Online survey at Survey Monkey
  - » Hosting on CCG, IWHCT, EMH, IWC and MLAFL websites



Appendix 7

## Individualised Care Plan

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Available to view or download from:

<http://www.isleofwightccg.nhs.uk/our-priorities/end-of-life-care.htm>

If you would like a hard copy sent to you, please email: [eolc.strategy@iow.nhs.uk](mailto:eolc.strategy@iow.nhs.uk)

Or call 01983 552064 to request a copy.

Appendix 8

## IOW NHS Trust End Of Life Care Policy

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Available to view or download from:

<http://www.isleofwightccg.nhs.uk/our-priorities/end-of-life-care.htm>


If you would like a hard copy sent to you, please email: [eolc.strategy@iow.nhs.uk](mailto:eolc.strategy@iow.nhs.uk)

Or call 01983 552064 to request a copy.

## Appendix 9

## Memorandum of Understanding

Made and entered into between the undersigned parties, and sets forth guidelines concerning how the arrangements will function practically regarding each party's role and responsibilities for a child who has been assessed as suitable for admission to the hospice bed, under the care of the paediatric palliative care team:

Name	Nigel Hartley	
Position	Chief Executive Earl Mountbatten Hospice	
Address	Earl Mountbatten Hospice (EMH), Halberry Lane Newport Isle of Wight PO30 2ER	
Telephone	01983 535331	
E-mail	<a href="mailto:nigel.hartley@iwhospice.org">nigel.hartley@iwhospice.org</a>	

Name	Karen Baker	
Position	Chief Executive	
Address	Isle of Wight NHS Trust St Mary's Hospital Parkhurst Road Newport Isle of Wight PO30 5TG	
Telephone	01983 822099	
E-mail	<a href="mailto:karen.baker@iow.nhs.uk">karen.baker@iow.nhs.uk</a>	

### Background

Isle of Wight families with children or young adults with life-shortening conditions wish to be offered a choice of places that can support their child at the end of life, and/or an appropriate cool room and supported space for parents and siblings to spend time with the child's body after death. In addition to the options of hospital, home, or Naomi House Children's Hospice that already exist, EMH are able to offer the use of a hospice bed. The request for this local provision originates from the Island families themselves.

The choice of EMH as a care setting must be made by the family with the full knowledge that this option is not a specialist paediatric palliative care setting, and the service provided will be similar to that which the child would receive at home. All clinical care will be provided by the Isle of Wight NHS Trust Children's Community Team (Children's Community Team) who will have a 24 hour, seven day per week presence in EMH whilst the child is resident. If the care required in the setting extends beyond the clinical capacity of the Children's Community Team then arrangements would be made to transfer the child to the acute paediatric ward.

EMH is willing to make such provision within its facilities, whilst the Isle of Wight NHS Trust (IOW NHS Trust) provides all clinical care to the child. The facilities provided will only be available for children who are near the end of life and have a focus of care that is comfort only without active interventions.

This Memorandum of Understanding (MoU) is specifically designed to support the care pathway of one child at any time.

### Scope

The parties involved and how they relate to each other:

- EMH provides hotel facilities for the child and their family when end of life care is required.
- The Children's Community Team delivers all nursing and clinical care in the EMH setting in parity to that which would be delivered within the Community.
- EMH to provide a cool room facility of a supported space for parents and siblings to spend time with the child's body after death. Support is provided by hospice staff, NHS staff & appropriately trained volunteers.
- A small team of senior clinical staff from EMH will form a rota & be on call for the children's community team when it is expected that a child & family will require the facilities at EMH

### Nursing and Responsibilities of Earl Mountbatten Hospice

- To offer safe and appropriate accommodation for the child and their family, in the form of a suite of two rooms, when possible & depending on room availability one for the child and one for the family. The child's room will be able to be decorated with posters and toys to their choosing to make it as congenial as possible. The family room will have a bed to allow at least one parent to stay overnight. The rooms will be co-located in an area of EMH which will have access restricted. These arrangements have been discussed and agreed with the CQC.

- EMH staff will give general support and guidance on the use of EMH facilities; EMH staff will not give direct clinical or nursing care. The exception to this will be caring for the child's body after death as appropriate.
- In an emergency EMH staff will act within their professional capability and competence to support the Children's Community Team and child's family.
- When a care plan has been written and agreed between the IOW NHS Trust and family, EMH staff involvement in that care plan will be limited to the provision of excellent customer service and the provision of hotel facilities such as making provision for nutritional and housekeeping requirements.
- EMH volunteer staff who may come into contact with the child at EMH have undergone the necessary safeguarding children training and this satisfies CQC requirements.

### Roles and Responsibilities of The Isle of Wight NHS Trust

- The Children's Community Team will provide 24 hour, seven day per week clinical care and support to the child and their family when the family identify that their choice of setting for end of life care is EMH.
- Recognising that the EMH adult clinical team are not trained in paediatric care, including emergency care, there will be a paediatric team member present at all times who is able to provide immediate management of unexpected clinical situations whilst awaiting the arrival of other paediatric team members and/or the ambulance service. This includes the administration of relevant medicines where necessary eg buccal midazolam.
- The Children's Community Team will provide continuous (ie 24-hour a day, 7 days a week) paediatric care for the whole period of the child's stay at the hospice.

### Items of Mutual Understanding

- It is important to note that EMH does not employ paediatricians or paediatric nurses. Paediatric staffs with the requisite qualifications and experience are employed within the IOW NHS Trust and support the Island families through the hospital and community services. Furthermore, there are professional restrictions on adult registered nurses, which EMH employs, giving clinical support to children.
- It is essential that the child is never left unaccompanied, whilst the principal responsibility for this lies with the parents, the Children's Community Team must have a 24 hour, seven day per week presence in the hospice.

- EMH requests that the care plan is shared and is explicit in detailing in an emergency who is responsible for additional clinical support, their availability (particularly out of hours) and their contact details. Such details should also be shared with and understood by the family to avoid misunderstanding or erroneous expectations.
- The provision of these facilities will be at no cost to the IOW NHS Trust.
- Due to access restrictions EMH only has two rooms that they are able to use for the care of the child.
- Should the hospice be at capacity, admission of the child will be deferred until such time as a suitable bed is available. It will remain the responsibility of the Children’s Community Team to agree an alternative care plan with the child’s family, until a hospice bed is available.
- Should the Children’s Community Team be unable to provide 24-hour a day, 7 days a week paediatric care for the whole of the child’s admission, then referral for admission to the hospice will be denied.
- EMH reserves the right to withdraw and/or amend this Memorandum of Understanding at any time.

**Terms of Agreement**

This agreement will start on

**Authorised Representatives**

By signature below the person certifies that the individuals listed in this document as representatives of the organisations are authorised to act in their representative areas for matters related to this agreement.

The parties hereto have executed this instrument.

**Party A: Earl Mountbatten Hospice**

**Signature** .....

**Date**.....

**Party B: Isle of Wight NHS Trust**

**Signature** .....

**Date**.....

## References

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- <sup>1</sup> <http://www.ncpc.org.uk/news/every-moment-counts-new-vision-coordinated-care-people-near-end-life-calls-brave-conversations>
- <sup>2</sup> 'One Chance to Get It Right' LACDP, June 2014
- <sup>3</sup> National End of Life Care Intelligence Network: [http://www.endoflifecare-intelligence.org.uk/data\\_sources/place\\_of\\_death](http://www.endoflifecare-intelligence.org.uk/data_sources/place_of_death)
- <sup>4</sup> 'One Chance to Get It Right' LACDP, June 2014
- <sup>5</sup> A Mandate from the Government to NHS England 2015–16: <https://www.gov.uk/government/publications/nhs-mandate-2015-to-2016>
- <sup>6</sup> Death registrations in England and Wales, selected data tables 2010, Office for National Statistics (ONS), 2011, London
- <sup>7</sup> Gomes B and Higginson I (2008) Where people die (1974–2030): past trends, future projections and implications for care. Palliative Medicine 22: p33–41
- <sup>8</sup> Hughes-Hallet T, Craft A and Davies C. (2011) Palliative Care Funding Review; Funding the Right Care and Support for Everyone
- <sup>9</sup> Mortality Statistics: Deaths Registered in England and Wales (Series DR), 2012: [www.ons.gov.uk/ons/rel/vsob1/mortality-statistics--deaths-registered-in-england-and-wales--seriesdr-2012/index.html](http://www.ons.gov.uk/ons/rel/vsob1/mortality-statistics--deaths-registered-in-england-and-wales--seriesdr-2012/index.html)
- <sup>10</sup> Gomes B, Calanzani, N and Higginson IJ (2011). Local preferences and place of death in regions within England 2010. Cecily Saunders International, London.
- <sup>11</sup> British Social Attitudes Survey: [http://bsa-30.natcen.ac.uk/media/36320/bsa\\_30\\_dying.pdf](http://bsa-30.natcen.ac.uk/media/36320/bsa_30_dying.pdf)
- <sup>12</sup> The National Council for Palliative Care and the National End of Life Care Intelligence Network (2009–10) National Survey of Patient Activity Data for Specialist Palliative Care Services
- <sup>13</sup> Department of Health 2008. End of Life Care Strategy: Promoting high quality care for all adults at the end of life
- <sup>14</sup> Neuberger J. More care, less pathway: a review of the Liverpool care pathway. 2013.
- <sup>15</sup> <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>
- <sup>16</sup> <http://www.hospiceuk.org/what-we-offer/commission-into-the-future-of-hospice-care>

- <sup>17</sup> Results of monitoring of funding for end of life care 2010 to 2011: PCT returns on SPC spend in 2010/11, <https://www.gov.uk/government/publications/results-of-monitoring-of-funding-for-end-of-life-care-2010-to-2011>
- <sup>18</sup> Isle of Wight Joint Strategic Needs Assessment (JSNA) 2013.
- <sup>19</sup> National Survey of Bereaved People (VOICES) 2011–2012 ONS
- <sup>20</sup> Palliative Care Funding Review, 2011
- <sup>21</sup> Results of monitoring of for end of life care 2010 to 2011: PCT returns on SPC spend in 2010/11, <https://www.gov.uk/government/publications/results-of-monitoring-of-funding-for-end-of-life-care-2010-to-2011>
- <sup>22</sup> Scherder EJ, Bouma A (1997). 'Is funding decreased use of analgesics in Alzheimer's disease due to a change in the affective component of pain?' *Alzheimer Disease and Associated Disorders*, 11, 171–74.
- <sup>23</sup> Dementia – A state of the nation report on dementia care and support in England, November 2013
- <sup>24</sup> Learning from PPO Investigations – End of Life Care, Prisons and Probation Ombudsman, 2013
- <sup>25</sup> RCGP Commissioning Guidance in End of Life Care, 2013
- <sup>26</sup> Jo Fitzgerald, People Hub, 'Personal Health Budgets are not all about the money'

Isle of Wight End of Life Care Strategy **2015–2020**

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<http://www.isleofwightccg.nhs.uk/our-priorities/end-of-life-care.htm>

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Or call 01983 552064 to request a copy.