NHS
West Hampshire
Clinical Commissioning Group

West Hampshire CCG & Southampton City CCG End of Life Care Strategy 2015-2020

Quality services, better health

This paper sets out for the people of West Hampshire what the implications of the Southampton City CCG & West Hampshire CCG End of Life Care Strategy Refresh are for them.

It has been updated to reflect the new national framework, published in the Autumn of 2015.

The 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).”

(Every Moment Counts, National Voices/ NHSE 2015)

What we mean by End of Life and End of Life Care

End of Life:

People are 'approaching the end of life' when they are likely to die within the next 12 months (GMC 2010*). This includes people whose death is imminent (expected within a few hours or days) and those with:

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

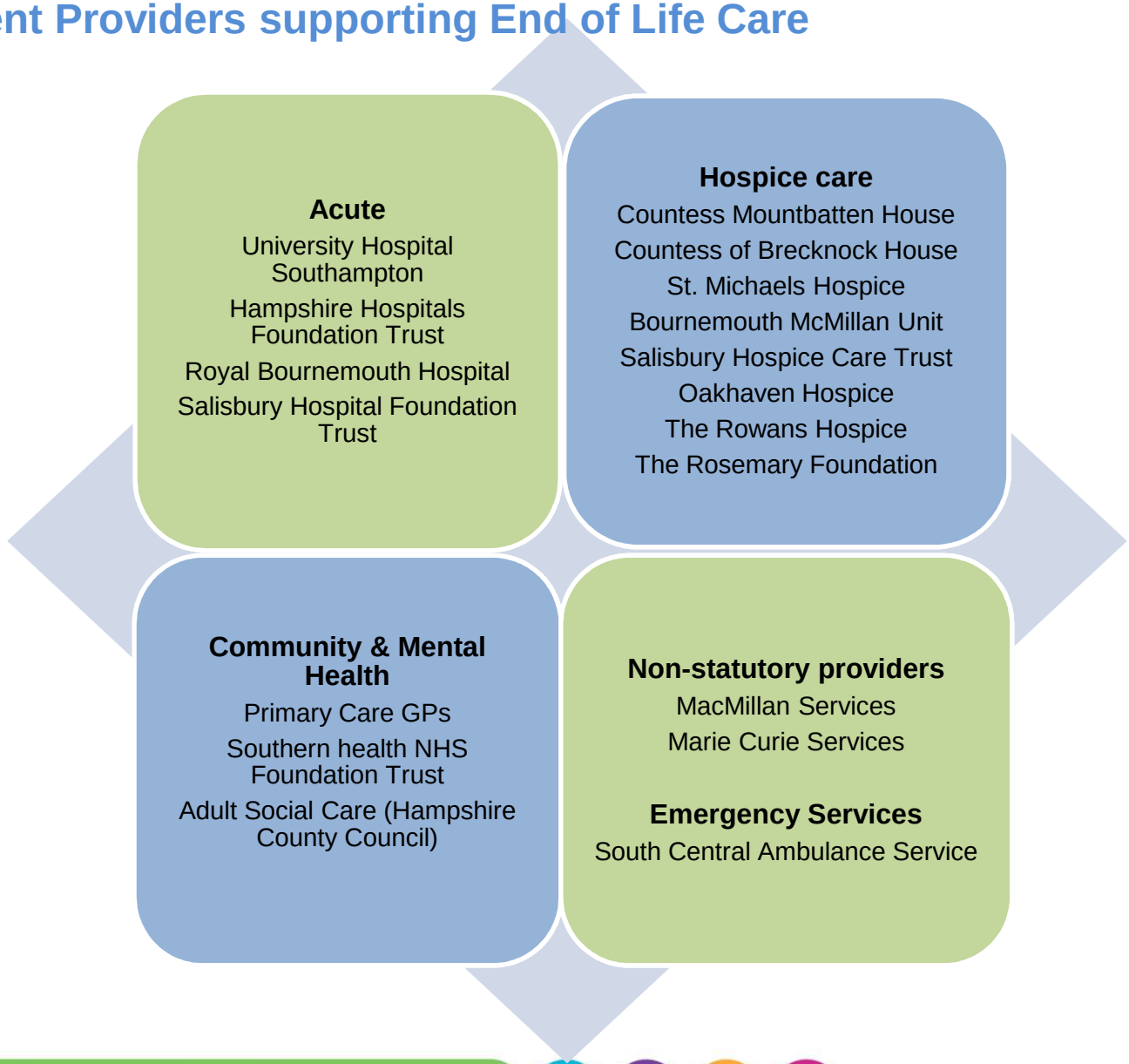
*http://www.gmc-uk.org/static/documents/content/Treatment_and_care_towards_the_end_of_life_-_English_0914.pdf

End of life care is care that:

Helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.

National Council for Palliative Care 2006

Current Providers supporting End of Life Care

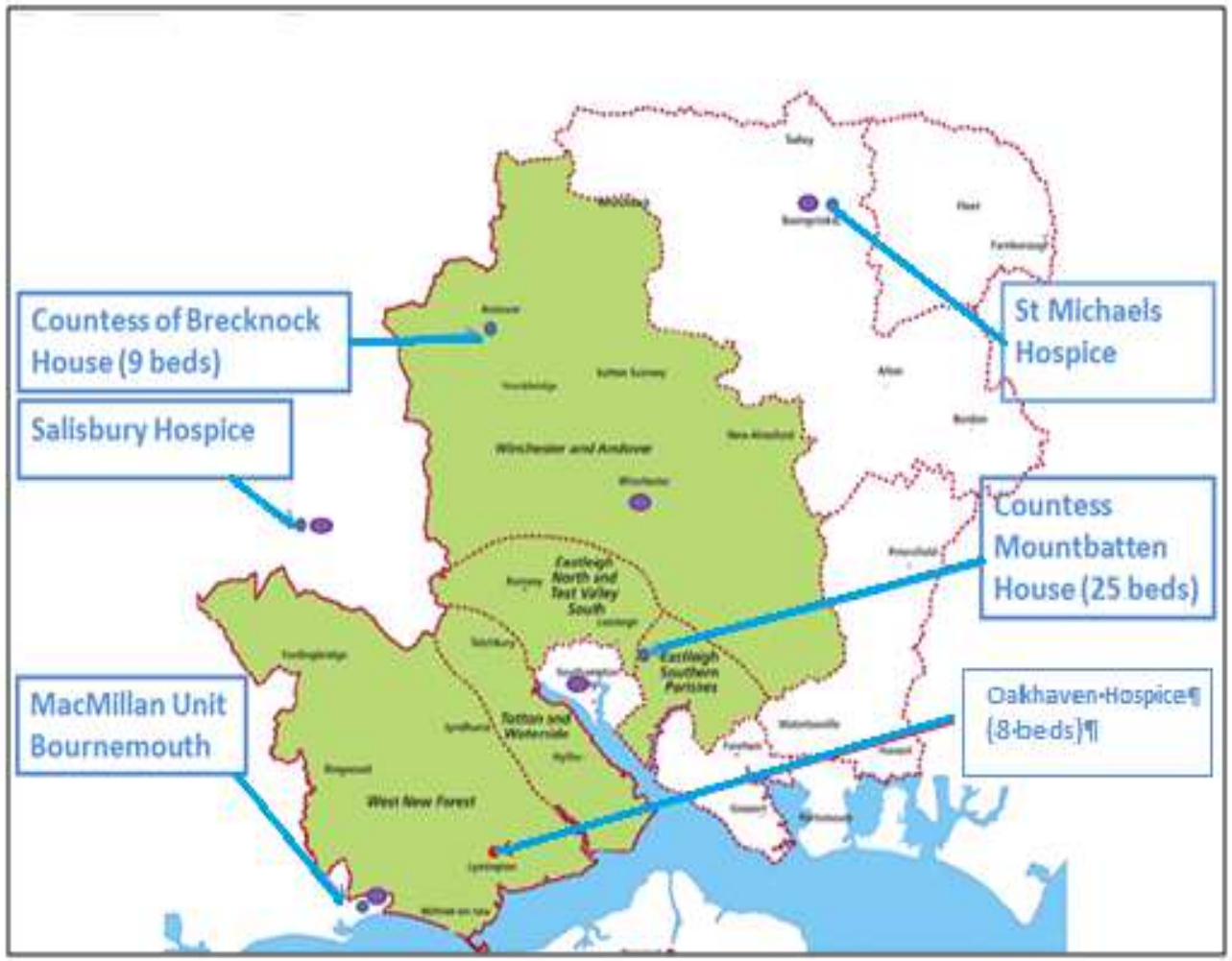


Current Community provision

Services provided:

- General Palliative Care nursing and therapy through Community Care Team (8am-11pm);
- Provision of Generalist step up/down End of Life beds at Romsey Hospital;
- End of Life Bed provision at Lymington with support from Oakhaven Hospice;
- Night sitting service in New Forest & Winchester

Current Acute and Hospice provision



Services provided:

- Specialist Palliative Care Inpatient Beds;
- Community Palliative Care Team;
- Hospital Palliative Care Team;
- Day Care services; and
- Bereavement Care
- Services primarily focus on malignant disease;
- Some inequity of service model, such as Hospice at Home.

Needs Assessment

Demographics:

- 543,354 people registered in WHCCG
- 93% White British with a rising ethnic population;
- Religion claimed by 66% population;
- Population of ≥65 = 118,734 (22% population vs 17% England);
- "Oldest old" ≥ 85 = 17,259 (3% population versus 2% England);
- Deprivation affects 14,318 older people (10.4% of older population);
- Life expectancy (81.7 ♂ and 85.2 ♀);
- Healthy Life Expectancy is 68.3 ♂ and 69.7 ♀;

- ♀ live longer than ♂, but spend more years in unfavourable health (15.5 versus 13.4 years);
- Number of people aged 65 and over projected to increase by 26% between 2012 and 2022 (England 22%)

Deaths:

- 5098 deaths in 2013 (0.9% population);
- 3863 (76%) of deaths "expected";
- Death rate 440 per 100,000 (England 550/100,000);
- 73% deaths in people aged 75+

Cause of death:

- 28% cancer
- 27% circulatory disease
- 13% respiratory disease
- 32% "other"

Place of death:

- 47% die in hospital
- 25% care home
- 21% home
- 5% hospice
- 2% other

EOLC Spend:

West Hampshire CCG spend approximately 1.2% of the whole budget on EOLC Hospital care most significant element of cost, but the least preferred location of death

Need Assessment: Key messages

Number of people aged 65 and over projected to increase by 26% between 2012 and 2022 (England 22%)

3863 of 5098 deaths (76%) in West Hampshire are "expected"

73% deaths in people aged 75 and over

28% people die from malignant disease, 62% from other causes

47% die in hospital, 25% care home, 21% home, 5% hospice, 2% other

Hospital care most significant EOLC cost element, but the least preferred location of death

What people say

Hospice at Home - West Hampshire CCG local survey in 2014 shows;

- 13/13 people died in the place of their choice
- 13/13 rated the service as excellent
- 13/13 said that nothing could have been done better
- 13/13 said that they felt well supported after the death of their loved one

National Survey of Bereaved People (VOICES) Office for National Statistics 2012 . Headline results for West Hampshire CCG – experiences of care of the deceased in the last three months of life. The numbers respondents who:		England averages
Rated the overall quality of care as outstanding or excellent	45%	43.2%
Rated the overall care from district and community nurses as excellent And from GPs	77.5% 78.8%	78.6% 72.4%
Considered they were shown dignity and respect by hospital doctors And from hospital nurses	61% 52.9%	57.9% 49.9%
Felt that they had received enough help and support from the health care team at the actual time of death	61.1%	59.8%
Felt they had been dealt with in a sensitive manner after the death	94.3%	93.5%
Reflecting over the last three months of the deceased's life, felt they were involved in decisions about care as much as they would have wanted	77.6%	77.9%

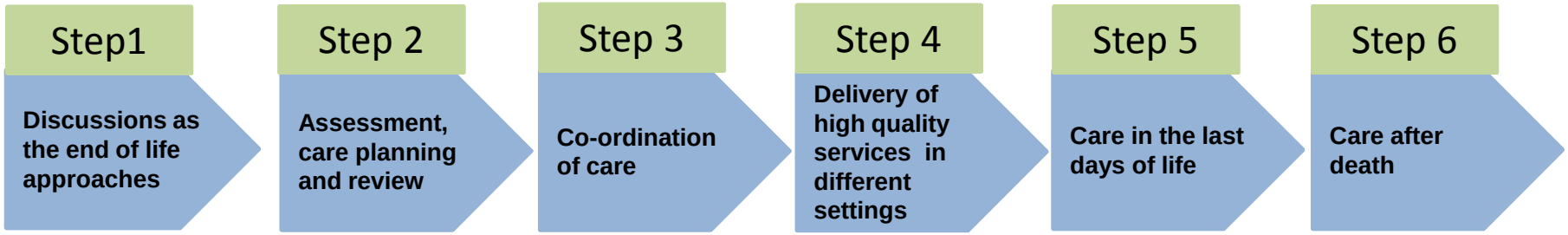
Ambitions for end of life and palliative care
(a national framework for local action 2015-2020)

The six ambitions include a statement to describe the ambition in practice, primarily form the point of view of the person nearing end of life.

'I, and the people important to me, have opportunities to have honest, informed and timely conversations and to know that I might die soon. I am asked what matters most to me. Those who care for me know that and work with me to do what's possible.'	**Ambition 1**
'I live in a society where I get good end of life care regardless of who I am, where I live or the circumstances of my life.'	**Ambition 2**
'My care is regularly reviewed and every effort is made for me to have the support, care and treatment that might be needed to help me to be as comfortable and as free from distress as possible.'	**Ambition 3**
'I get the right help at the right time from the right people. I have a team around me who know my needs and my plans and work together to help me achieve them. I can always reach someone who will listen and respond at any time day or night.'	**Ambition 4**
'Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and compassionate care.'	**Ambition 5**
'I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways.'	**Ambition 6**

Sourced from 'Ambitions for Palliative and End of Life Care'. National Palliative and End of Life Care Partnership
www.endoflifecareambitions.org.uk

Department of Health, 2008, end of life strategy, 'The Six Steps'



Open, honest communication

Identifying triggers for discussion

Agreed care plan and regular review of needs and preferences

Assessing needs of carers

Strategic coordination

Coordination of individual patient care

Rapid response services

High quality care provision in all settings

Acute hospitals, community, care homes, hospices, community hospitals, secure hospitals and hostels

Ambulance services

Identification of the dying phase

Review of needs and preferences for place of death

Support for both patient and carer

Recognition of wishes regarding resuscitation and organ donation

Recognition that end of life care does not stop at the point of death

Timely verification and certification of death or referral to coroner

Care and support of carer and family, including emotional and practical bereavement support

DoH, 2008 End of Life Care Strategy, http://webarchive.nationalarchives.gov.uk/20130107105354/http:/www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_086345.pdf

West Hampshire CCG End of Life Care Model (based on 'The Six Steps')

Early Communication, Planning and Information Advice and Guidance

Learning from patients, families and practitioners

Good support at the end of life.

Early Communication and Planning

- Early identification of people approaching the end of life.
- Inclusion of people on Case Management Register.
- Early communication, support, information and advice.
- Effective and well governed sharing of patient information.
- Proactive and person centred care planning noting advanced decisions made by the person.
- Carers assessments and support.
- Use of Personal Budgets.
- Active listening to the person concerned and use of their plans and wishes in care plans.

Steps one and two:

- ***Step 1 Discussions as the end of life approaches.***
- ***Step 2 Assessment, care planning and review.***

Care At End of Life

- Equity of access across life limiting conditions.
- Consistent overnight and out of hours specialist advice and support.
- Sustainable options for care at home in the last days of life.
- Care after death.

Steps five and six:

- ***Step 5 Care in the last days of life.***
- ***Step 6 Care after death, bereavement support.***

Proactive intervention supports people to manage their own condition, to remain as independent as possible and to prepare for the end of life.

Individualised and Proactive Intervention

- Anticipatory prescribing.
- Develop Integrated Care Team and wider service core End Of Life Care skills.
- Well Co-ordinated care and good communication - end of life care named workers.

Steps three and four:

Step 3 Coordination of care for individual patients.

Step 4 Delivery of high quality services in different settings.

How the ‘six ambitions’ link to the Department of Health ‘six steps’

To ensure that our proposed model for delivering end of life care (based on the DH 2008, ‘Six Steps’) meets the requirements of the ‘Six Ambitions’ framework, the following analysis has been undertaken . It shows that the outcomes are aligned however, as the ‘Ambitions’ outcomes are based around the person reaching end of life, the DH ‘Six Steps’ also clearly addresses carers needs and provides a more functional basis for end of life care, with the six ambitions focussing on outcomes.

DH 2008 (Six Steps)	Ambitions 2015-2020 (Six Ambitions)	What’s needed
Step 1 **Discussions as the end of life approaches:** Open, honest communication Identifying triggers for discussion	**Ambition 1** ‘I, and the people important to me, have opportunities to have honest, informed and timely conversations and to know that I might die soon. I am asked what matters most to me. Those who care for me know that and work with me to do what’s possible.’	(Ambition 1) • Honest conversations • Clear expectations • Helping people take control • Systems for person centred care • Access to social care • Integrated care • Recognition that good end of life includes bereavement
Step 2 **Assessment, care planning and review:** Agreed care plan and regular review of needs and preferences Assessing needs of carers	**Ambition 3** ‘My care is regularly reviewed and every effort is made for me to have the support, care and treatment that might be needed to help me to be as comfortable and as free from distress as possible.’	(Ambition 3) • Skilled assessment and symptom management • Priorities for care of the dying person • Recognising distress, whatever the cause • Addressing all forms of distress • Rehabilitative palliative care • Specialist palliative care

How the ‘six ambitions’ link to the Department of Health ‘six steps’

DoH 2008 (Six Steps)	Ambitions 2015-2020 (Six Ambitions)	What’s needed
Step 3 **Co-ordination of care** Strategic coordination Coordination of individual patient care Rapid response services	**Ambition 4** ‘I get the right help at the right time from the right people. I have a team around me who know my needs and my plans and work together to help me achieve them. I can always reach someone who will listen and respond at any time day or night.‘ **Also Ambitions 1 & 5**	(Ambition 4) • Shared records • A system-wide response • Clear roles and responsibilities • Continuity in partnership (joined up thinking and joined up care) • Recognising that everyone matters
Step 4 **Delivery of high quality services in different settings** High quality care provision in all settings Acute hospitals, community, care homes, hospices, community hospitals, secure hospitals and hostels Ambulance services	**Ambition 2** ‘I live in a society where I get good end of life care regardless of who I am, where I live or the circumstances of my life.’ **Also Ambitions 3 & 5**	(Ambition 2) • Using existing data • Generating new data • Population based needs assessment • Community partnerships • Unwavering commitment • Person centred outcome measurement

How the ‘six ambitions’ link to the Department of Health ‘six steps’

DoH 2008 (Six Steps)	Ambitions 2015-2020 (Six Ambitions)	What’s needed
Step 5 **Care in the last days of life** Identification of the dying phase Review of needs and preferences for place of death Support for both patient and carer Recognition of wishes regarding resuscitation and organ donation	**Ambition 5** ‘Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and compassionate care.’ **Also Ambition 1**	Ambition 5 • Professional ethos • Knowledge based judgement • Awareness of legislation • Support and resilience • Using new technology • Executive governance
Step 6 **Care after death** Recognition that end of life care does not stop at the point of death Timely verification and certification of death or referral to coroner Care and support of carer and family, including emotional and practical bereavement support	**Ambition 6** ‘I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways.’	Ambition 6 • Compassionate and resilient authorities • Practical support • Public awareness • Volunteers

Our aims

Aims	DH step	Ambition	How
Ensure that people are supported to have open, honest and timely conversations as they near end of life.	1/5	1	Through education , training and support for all involved in EOL care
Ensure that there are agreed and shared assessments and care plans that detail the wishes of the dying person and are accessible by those involved in their care.	2/3	3 /4	Shared records 24/7 access to information Personalised care planning
Ensure that assessments and care plans are regularly reviewed, updated and shared. This is important as people may change their mind as they progress towards the end of their life.	2/3	3 /4	Integrated working Care co-ordination Shared records
Ensure that carers needs are assessed, recorded, shared, reviewed and that carers and family members are supported effectively.	2/3	3 /4	Integrated working Voluntary sector involvement Shared records
Ensure that there are a range of settings that can meet the needs and, wherever possible, the wishes of the individual as they reach the end of their life.	4/5	2 /4	Remodelling end of life services to maximise support to people to die at home, if they chose to do so
Reduce the numbers of people dying in acute beds by working with providers to support more people to either die at home (including residential homes) and accessing hospice care and support (both in the community and in hospice settings).	4/5	5	As above
Ensure that effective processes are in place following the death in any setting.	6	4	Education and training
Engage with communities to increase public awareness, community action and volunteering opportunities for supporting people reaching the end of their life and support for families and carers.	6	6	Work with the voluntary sector Co-produce information campaigns Support with training of volunteers

What we will achieve for West Hampshire CCG

Each person is seen as an individual
Individuals will have timely, honest and well-informed conversations about dying, death and bereavement. They will know what to expect as they reach the end of their life. Their family, friends, carers and other loved ones will be supported with preparing for loss, grief and bereavement. GP's and other trained professionals will have discussed and recorded individuals end of life preferences including supporting them with making advance directives. More people will be enabled to die in a place of their choosing.

Each person gets fair access to care
Access to end of life/palliative care will be equitable, regardless of diagnosis and protected characteristics. This may include young people when, following discussion with the patient and their family, adult services are more appropriate to their needs.

Maximising comfort and wellbeing
Paid carers and clinicians will have been trained, supported and encouraged to bring a professional ethos to end of life care. Professionals will be supported to use any new technology introduced to support end of life care. Those providing end of life care will understand and comply with legislation that seeks to ensure an individualised approach to end of life care. Those involved in supporting an individual will understand all forms of distress and take action to address these which may be emotional, psychological anguish, social and/or spiritual distress as well as pain management.

Care is co-ordinated
There are effective integrated systems in place for people nearing end of life. Effective assessment, care co-ordination, care planning and care delivery are supported by all services involved in their care and needs will be met in ways that are appropriate to the individual. Personal budgets will be available to support personalised care.

All staff are prepared to care
Arrangements will be in place to join up care between the NHS, social care and the voluntary sector. Everyone will be clear of their role and end of life care will interface seamlessly with bereavement services.

Each community is prepared to help
Public awareness of the difficulty that people face at the end of their life will support a better and wider understanding of the help that is available. Volunteers will be more integrated into end of life care.

Based on 'Ambitions for Palliative and End of Life Care'. National Palliative and End of Life Care Partnership
www.endoflifecareambitions.org.uk

We will know we have succeeded when people are able to respond positively to the following statements:

‘I, and the people important to me, have opportunities to have honest, informed and timely conversations and to know that I might die soon. I am asked what matters most to me. Those who care for me know that and work with me to do what’s possible.’	
‘I live in a society where I get good end of life care regardless of who I am, where I live or the circumstances of my life.’	
‘My care is regularly reviewed and every effort is made for me to have the support, care and treatment that might be needed to help me to be as comfortable and as free from distress as possible.’	
‘I get the right help at the right time from the right people. I have a team around me who know my needs and my plans and work together to help me achieve them. I can always reach someone who will listen and respond at any time day or night.‘	
‘Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and compassionate care.’	
‘I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways.’	

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