‘DYING MATTERS IN DEVON’

Co-ordinated by NHS Devon & Devon County Council

Strategy for Living Well Until the End of Life

2nd & Final Draft
September 2010 - 2015

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Draft

Document Control

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Strategy for Living Well Until the End of Life

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1. Introduction

1.1 This strategy, developed by NHS Devon and Devon County Council, in collaboration with statutory and voluntary partners and local stakeholders, sets out the vision for high quality care in Devon for all adults approaching the end of life.

1.2 The strategy dovetails with national and local strategies and agendas including:

- The Gold Standards Framework 2005
- The Liverpool Care Pathway for the Dying Patient (LCP)
- Preferred Priorities of Care (PPC)
- The national End of Life Care Strategy 2008
- Lord Darzi’s NHS High Quality Care for All: Next Stage Review 2008
- The national End of Life Quality Markers 2009
- The Department of Health – Route to Success in End of Life Care – Achieving Quality in Acute Hospitals 2010
- The Department of Health – Supporting People to Live and Die Well – a framework for Social Care at End of Life Care 2010
- Disability Discrimination Act 1995 & Mental Capacity Act 2009
- Six Lives: the Provision of Public Services for people with Learning Disability 2008-09
- Mencap’s Best Practice Guide for End of Life Care 2009
- NHS South West Strategic Health Authority ‘Improving Health: Ambitions for the South West 2008 -2013
- NHS Devon & Devon County Council Way Ahead document – Five Years of Improvement, Health and Social Care in Devon 2008 – 2013
- NHS Devon and Devon County Council’s Carers Strategy and Dementia Strategies 2008/9
- NHS Devon Quality ,Innovation, Productivity and Prevention Plan – for Urgent and End of Life Care
- Devon Rural Health and Well Being Strategy 2010 - 2013

1.3 Strategic Intention

We recognise that the last months, weeks, days, hours and minutes of life are a time of great need for people, and we will ensure this is also a time of great care, with high quality, sensitive and coordinated support from services that do everything possible to give people and their families choice, freedom from avoidable symptoms, and dignity at the end of life

1.4 The strategy will support strengthened health and social care commissioning arrangements in response to the needs of people and their carers in planning for the end of life and ensuring their preferences for end of life are met.`

1.5 A working definition of end of life care is as follows:

End of Life Services *are meant to support those with advanced, progressive, incurable illness to live as well as possible until they die. These are services that enable the supportive care and end of life care needs of both patient and their families and carers 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. This is not confined to discrete specialist services but includes those services provided as an integral part of the practice of any health or social care professional in any setting*.

1.6 This approach is underpinned by the principle of an active and compassionate approach to care that ensures respect for, and dignity of, the patient and their family and carers.

1.7 NHS Devon & Devon County Council aspires to the following underlying principles for dignity at the End of Life, recognising that individual's choices are fluid and may change during their pathway of care or, during changes in their personal circumstances and capacity:

Promoting Choice over

- Where people wish to die
- Who is with them when they die
- Involvement in decisions about their treatment

Ensuring Access to

- Expert information on their choices for end –of – life care
- High quality palliative care that is tailored to individual needs in whatever care setting
- Support for peoples families and carers

Promoting Individual's Control over

- Supporting people's wishes and preferences.
- How their symptoms and pain are relieved
- Planning the end of their life in advance if they so wish

1.8 **Pledge** - NHS Devon and Devon County Council will develop a **Good Death Charter** for end of life care (based on work informed by a public consultation in NHS North East). This provides a written statement of the rights and entitlements that should be honoured both from the individual preparing for death and for their carers and families. This should not only relate to medical and nursing care, but to behaviours of all agencies and sectors who deal with these issues. It is our intention that the NHS North East Charter will be adapted and amended in Devon following consultation with the public and users of services across the autumn of 2010.

1.9 Safeguarding and the Mental Capacity Act

NHS Devon and Devon County Council are committed to making improvements in services for people requiring palliative care across Devon. The Mental Capacity Act and Safeguarding Adult agenda are relevant to End of Life Care. The Mental Capacity Act provides the legal framework for decision- making when a person may lack capacity to make these decisions. Wherever possible the person should be enabled to reach appropriate decisions by themselves.

Where this is not possible, the Act offers guidance to ensure that those empowered to make decisions on behalf of someone else – including family members, carers, health and social care professionals and attorneys, always act in the best interests of those who lack mental capacity.

The Mental Capacity Act provides the mechanism for people to complete Advance Care Plans (a clear instruction refusing some or all medical procedures) and Advance Statements (an indication of the person's wishes).

The aim is to ensure that people who may be vulnerable to abuse or harm are protected by services which ensure that peoples human rights are respected.

In this context abuse includes acts of commission or omission, neglect, assault, sexual violence, financial abuse and discriminatory abuse. The abuse may be perpetrated by strangers, partners, friends, family members, people who use the services or people who provide the services.

2. National Context

2.1 The increase in the ageing population means that by 2030 deaths will outnumber births. In addition people are living longer with serious illness.

2.2 The majority of deaths follow a period of chronic illness such as heart disease, cancer, stroke, renal disease, respiratory disease, neurological disease or dementia

2.3 Nationally 3 out of 4 people die of non-cancer related illnesses, with minimal preparation for their end of life care. Most people are unable to die where they choose (usually in their own home, a care home or in a hospice). Most people die in hospital (60%), often going against the preference of the person and their families and carers, and making this a potential inappropriate use of a hospital bed.

2.4 People with Learning Disabilities make up 2% of the population with the over 60 yrs increasing by 36% nationally in the next decade. Some people with a learning disability have multiple disabilities or conditions related to the genetic cause of their learning disability. A number of the conditions associated with Learning Disability raise the risk of premature unavoidable death. These include congenital heart problems and epilepsy. There are also avoidable deaths when illnesses or complications are not diagnosed in a timely way. The 1995 Disability Discrimination Act makes it an anticipatory duty for Advance Care Plans and Advance Statements to be discussed ahead of time with people with a learning disability who are known to need palliative care.

2.5 A national survey undertaken for the BBC (2006) examined the issue of how many people identified their choice of place of death ahead of time. This revealed only 34% of people reported that they had discussed their wishes for a good death

2.6 In 2007 a national survey undertaken by the Health Care Commission identified 54% of complaints in acute hospitals were related to care of the dying resulting in a need for improvement particularly in acute care settings.

2.7 Lord Darzi's 2008 report 'High Quality for All' set out the vision for an NHS working in partnership with multi-stakeholders to provide care that is personal, effective and safe. The themes promoted in Lord Darzi's report of patient empowerment, greater choice, better information, more control and influence, as well as recommendations set out in the national End of Life Care Strategy underpin the end of life care strategy for NHS Devon & Devon County Council.

2.8 The Operating Framework for the NHS in England 2009 / 10 describes 2010 as a pivotal year for working in partnership with agencies to deliver extended and improved service provision for end of life care.

2.9 Recent work by the Nuffield Trust, suggests the work between health and social care to co-ordinate end of life care is crucial with opportunities for improved practice and economies of scale through joint working. They highlighted 30% of people who died were in receipt of some form of local authority funding in the year prior to death, with this increasing to 40% for older people.

2.10 The Nuffield Trust also found that access to social care intervention increases over peoples last year of life by 15% to 30% which is a significant challenge for health and social care services managing end of life care in Devon.

2.11 The Department of Health End of Life team have just launched the new framework for Social Care at the End of Life which seeks to promote the principles outlined in the 2008 End of Life Strategy with specific emphasis now on increasing user choices, personalisation and re-ablement agendas, which offer a more flexible, integrated and user led approach.

3. Regional Context

3.1 The Strategic Framework for Improving Health in the South West 2008/09 to 2010/11, *'Improving Health: Ambitions for the South West'* emphasises the principles that all services should be fair, personalised, effective, safe and locally accountable. We recognise that across the South West three out of five people say they would prefer to die at home, but fewer than one in five do so. The following aims are identified:

- Ensuring that everyone wherever possible supports peoples expressed choices, or aspiring wishes for place of care and death;
- Stopping unnecessary admissions to hospital in the last days of life;
- Helping people to ensure symptoms are well controlled;
- Community Nursing available 24/7
- Nursing equipment and palliative care drugs are available at short notice, including out of hours;
- Domiciliary care is available to support end of life care for terminally ill people and their carers, including respite care at home.

3.2 The NHS South West Strategic Framework sets out the following improvements in end of life care to be achieved against the national targets:

- All health communities to be able, by the 31st March 2011, to identify the number of people with a plan for their death and to report the percentage of cases where the preference about place of death has been delivered;
- Ensuring that at all times people can access the 'basic building blocks' for effective care (community nursing, equipment, drugs and patient plan) by 31st March 2011;
- Ensuring that, by responding to individual preferences, adult deaths in acute hospitals can be reduced by the minimum of 10% per annum for each of the next three years.

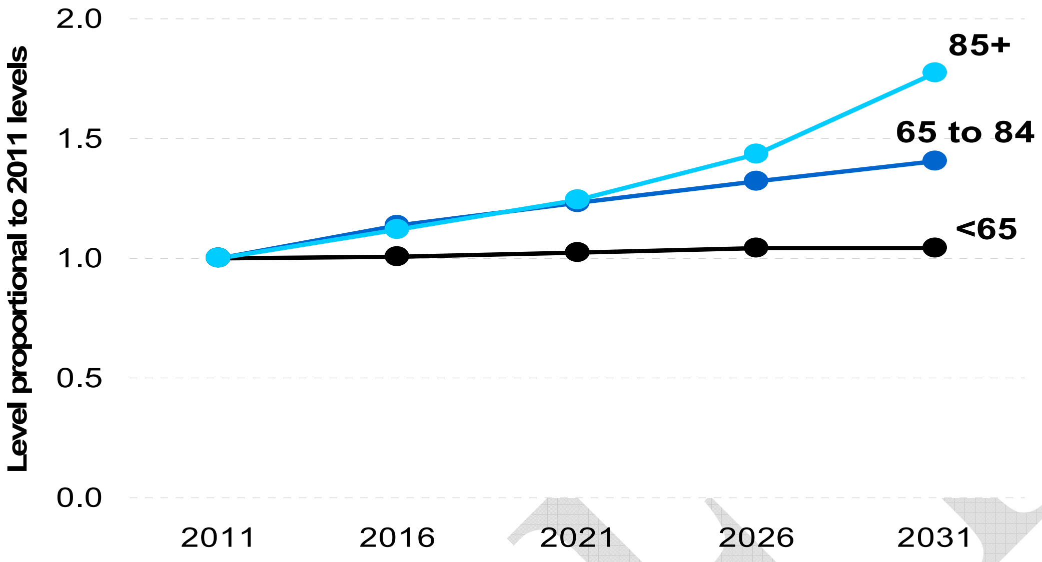
- Ensuring that, by providing support at home, unplanned admissions to hospital from nursing and care homes for those in the last 12 months of life is reduced by 10% per annum for each of the next three years.
- Ensuring arrangements are in place for assessing the needs and supporting carers.

4. Local Context

4.1 When calculating population statistics in End of Life care, the NHS and local authority use a variety of data sources. The main source is Public Health data using mortality information gathered from death certificates that indicate the primary cause of death. Data are also captured through contracting information gathered from our local hospitals. At present there is little information available on the volumes or cost of health care provided to people outside of hospital for people in the last year of life by the NHS (primary or community services), by the voluntary sector, or from social services. However recent advances in information capture and data linkage, and the development of the national End of Life Intelligence Network based in the South West Public Health Observatory will enable progress to be made in future years

4.2 Currently the population in Devon is over 755,000, and this is predicted to rise to 811,000 in the next five to ten years. We have a greater proportion of people in the older age groups and a lower proportion of younger age groups when compared with the national picture. The older population will grow by more than a third by 2021. In planning end of life care we need to consider 17% of our population are lone pensioners, with 12% of the county's 72,000 carers aged over 65 years. We know that by 2021 just over 26% of the total population will be aged 65 and over and, those over 80 years will rise by 8%. Figure 1 shows population projections by age group until 2031.

Figure 1. Expected growth in Devon's population by age group relative to 2011 levels



4.3 The population of Devon currently includes low proportions of people who belong to ethnic minority groups: 97.4% of the population describe themselves as White. The small proportions of people from mixed, Asian, Black, Chinese, and other ethnic groups creates the potential for their care needs to not be fully understood. It is important that thinking and planning around End of Life take into account the opinions and interests of people from these diverse groups.

4.4 We know that in the past four years on average we have had about 8,200 deaths in Devon per annum. The majority of these deaths occur in adults over the age of 65 years (see Figure 2), following a period of chronic illness. Figure 3 shows causes of death in Devon in relation to type of disease (ICD-10 chapters). A small number of deaths occur among people aged 19 and under, with the majority of those being in the 0–5 year old age group.

Figure 2. Percentage of deaths in Devon by age group

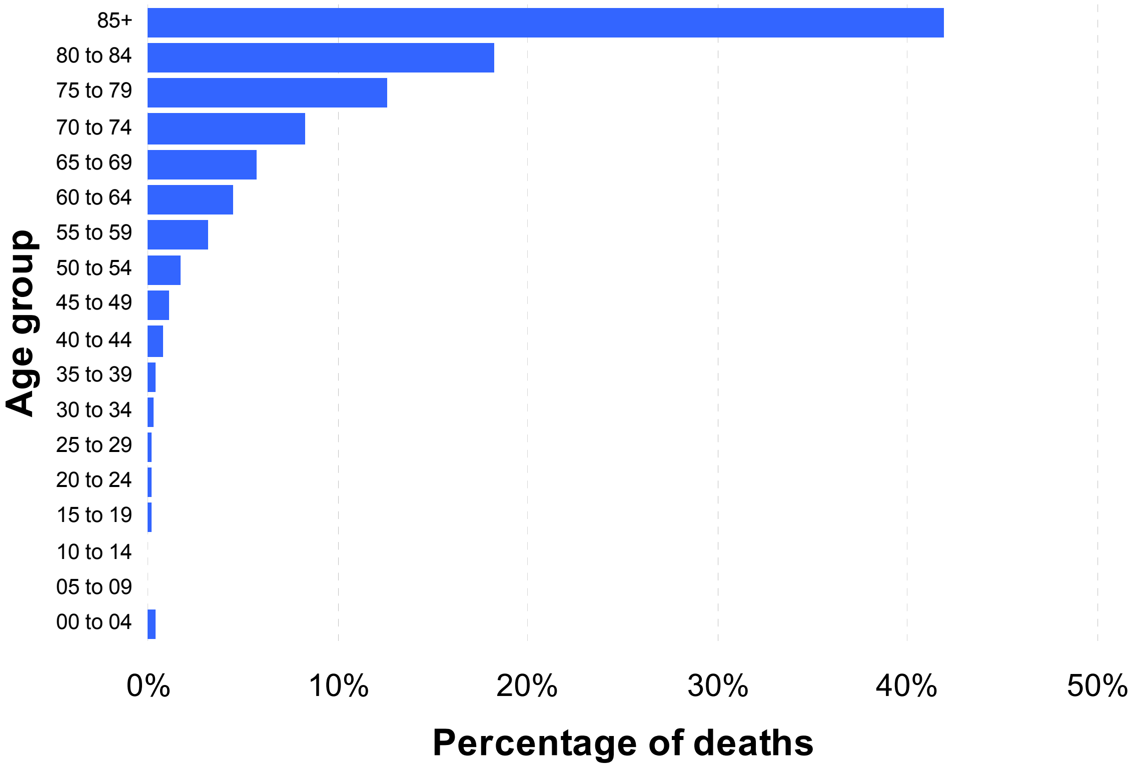
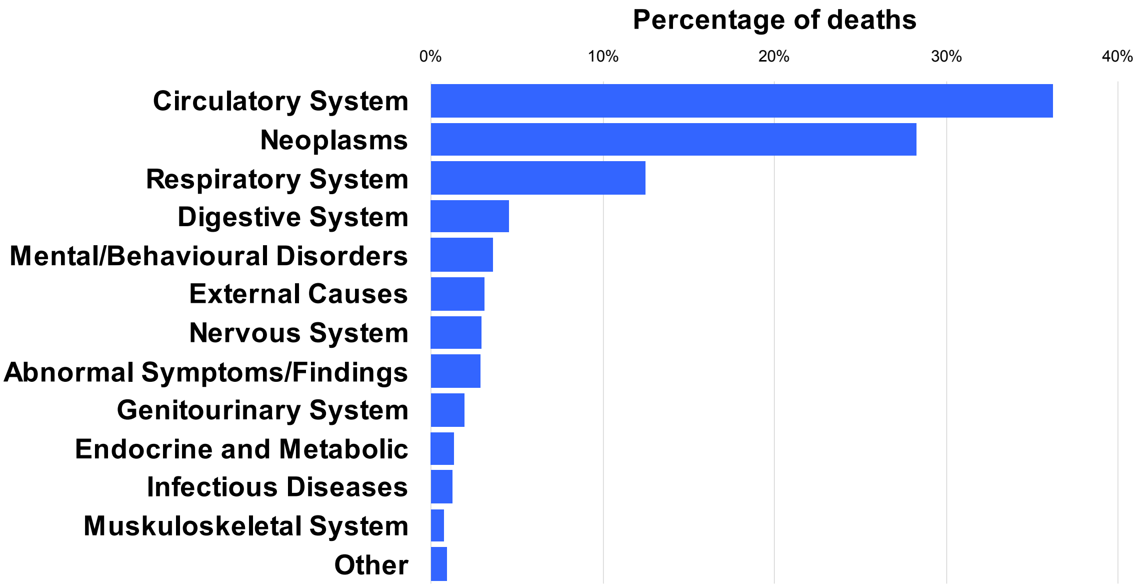


Figure 3. Percentage of deaths in Devon, by cause of death (ICD-10 Chapters)



4.5 Figures 4 and 5 demonstrate the place of death of these 8200 people showing Devon's comparison to the South West Average.

Figure 4. Place of death (%), South West region

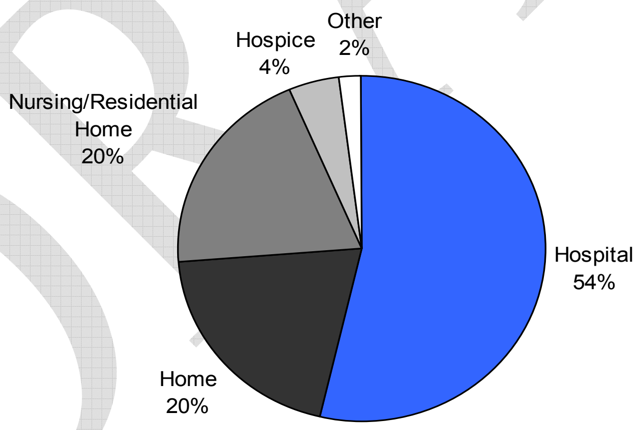
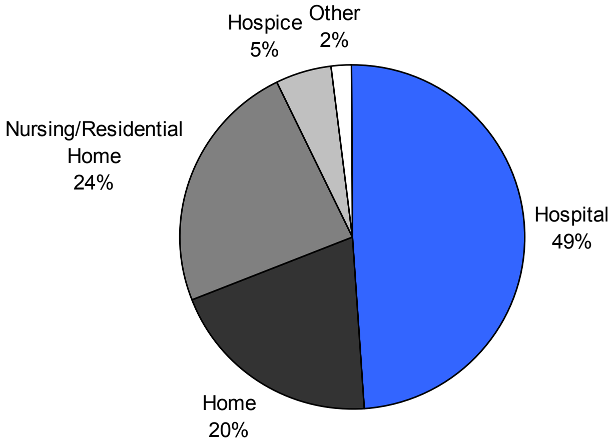


Figure 5. Place of death (%), Devon

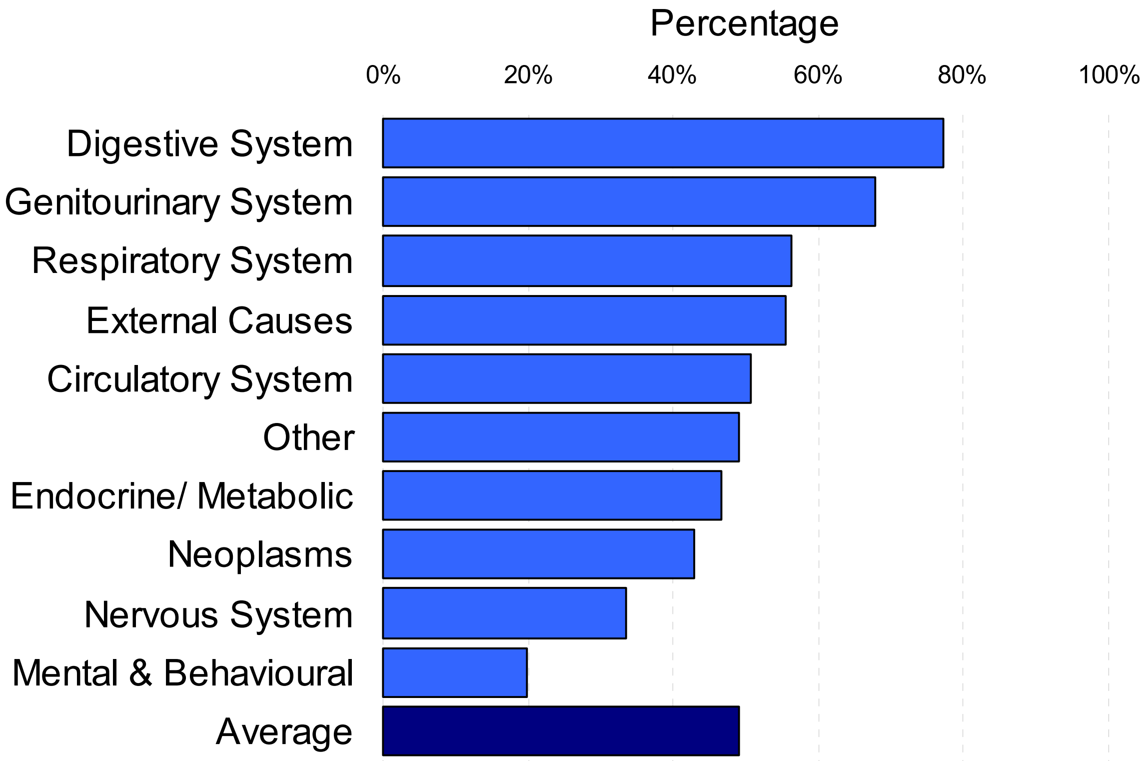


4.6 The data indicate 24% of deaths occur in Nursing and Residential Care Homes in Devon, including residential care homes for those with Learning Disabilities. Currently we have 267 Residential Care Homes for the Elderly, 80 Residential care homes with dual registration for Nursing. 182 of the Care Homes are registered for the Elderly Mentally Ill (EMI)

These figures contrast with national data on people's expressed preferences about place of death, with 64% of people preferring to die at home, 21% in a hospice and only 4% in hospital.

4.7 People who die of some conditions are more likely to die in hospital than those with other conditions. For example, more than three-quarters of people who die of diseases of the digestive system die in hospital, whereas less than half of people who die of cancer die in hospital (see Figure 6)

Figure 6. Percentage of people dying in hospital in relation to specific causes of death



4.8 The Care Quality Commission Local Area Market Analyser (LAMA) 2009/10 for residential, nursing and domiciliary care provision indicates the total capacity of these beds as being 7,717. The Office of National Statistics mid-year population estimate for 2009 was that there were 163,800 people aged 65 years and older living in Devon Local Authority area, which means approximately 5% of the Devon population aged 65 and older are residing in nursing and care homes

4.9 At present we do not have information on all the people in care homes in Devon within our social care management systems, only those who we either fund or commission care for. On residents who are self-funding we have little or no information.

4.10 Although no formal survey of the health status of elderly people in care homes throughout Devon has been undertaken, we anticipate their needs will be in line with published information that indicates:

- 1 in 5 people aged 65 will die in a care home
- Residents are increasingly frail and dependent
- On average over 50% of residents die within 2 years of admission

- One quarter of residents are confused, incontinent and immobile

These numbers suggest a large amount of end of life care is managed in this care sector, and there are suggestions that a high proportion of this group may be people in the end of life stages of dementia.

4.11 The Dementia UK report identified that one in 20 people over 65, and one in five over 80, were affected by dementia. In Devon estimates indicate that more than 12,000 people will have dementia currently, rising to more than 17,000 in 2021. This client group and their carers need to be much more involved in planning end of life care inside and outside of residential and nursing care in the future.

4.12 People with Learning Disabilities are more likely to die in their early adult years, due to difficulties associated with epilepsy, congenital heart defects and respiratory disease. Currently many people with a learning disability are living within residential settings having moved there from the family home, or long stay hospital; this is now changing. People with a learning disability are now renting a property or buying their own home rather than moving into residential care. Yet others are actually moving out of residential care into their own homes. This means that reasonable adjustment for people with a learning disability will need to be made in all the end of life care scenarios being discussed.

4.13 We know that life expectancies and mortality rates in Devon, like elsewhere in the country, differ according to the level of deprivation people experience. In Devon the average mortality rate is 5.03 per 1000 (that is, approximately 5 people per 1000 die every year). In the most affluent 20% of the population the mortality rate is lower, 4.33 per 1000; in contract, in the most deprived 20% of the population it is much higher, 7.26 per 1000.

4.14 These numbers reflect underlying differences in where, when, and from what people from different social backgrounds die. For example, people who die of cancer have a 20.4% chance of dying at home if they are in the most deprived fifth of the Devon population and 26.9% chance if they are in the most affluent fifth. Compared to the most affluent fifth, people who die of cancer and are in the most deprived fifth are more likely to die in a hospice (23.8% versus 16.4%) and less likely to die in a nursing or residential home (3.3% versus 9.2%). It is important that potential social inequalities in provision and take-up of End of Life care are taken into account.

5. The Vision for the Future – Improving Care to the Level of the Best

5.1 The strategy covers a situation where any person, from diagnosis to the advanced non curative stage of **any life limiting disease**, in any setting at any stage, lives well in the place of their choosing, (within the legal framework).

5.2 The thrust of the strategy for the future will be on improving care to the level of the best, with a combined health and social care approach. Specialist teams will be working with Acute Trusts, Community Nurses, Mental Health and Learning Disability teams and Complex Care teams, GPs, social care, domiciliary workers, the community and voluntary organisations to ensure that the Devon population receives high quality reliable care at the end of life, and retains a degree of control, dignity and choice(when realistic and appropriate).

5.3 To facilitate this aim the multi-agency partner organisations will endeavour to support staff who will be delivering the care in the most effective way possible. The services provided will be equitable in terms of access, place of delivery, and across all causes of end stage disease. Services will be provided in a timely fashion, with respect for the patient, family and carers and other professionals at all times.

5.4 The multi-agency partner organisations envisage a service provision across NHS Devon PCT and Devon County Council which reflects best clinical practice, delivered by supported, appropriately skilled professionals with access to all the therapeutic drugs, equipment and social support when required, in the patients chosen place of care.

5.5 Partner organisations and local communities will be encouraged during 2010 / 11 to join the NHS Devon and Devon County Council public and organisational awareness campaign to 'Live well until the end of life in Devon' – 'Dying Matters in Devon 2010', declaring our joint intent and actions. This campaign is part of our Devon links with the National Council for Palliative Care's 'Dying Matters Coalition' which brings together agencies and individuals to champion improved End of Life Care.

6. Scope of the End of Life Strategy

6.1 The scope of this strategy encompasses:

- Adults (defined for the purposes of this document as over the age of 18 years old) with any advanced, progressive, incurable disease, stroke, advanced cancer, chronic neurological conditions, mental illness including dementia, etc);

- Adults with learning disabilities

- Care provided in all settings (e.g. home, residential / care home, nursing home, hospice, acute hospital, community hospital, prison or other institution;

- Care provided in the last year(s) of life. No specific time limit should be imposed

- Patients, carers and family members (including care after bereavement).

6.2 End of life Care will also need to be commissioned across a number of other locations, for example hostels for the homeless, prisons and independent living homes

6.3 Children's end of life care needs are excluded from this strategy but will be addressed through the NHS Devon and Devon County Council's Children's Strategy

6.4 This strategy gives a broad overview of End of Life Care but consideration should be given to other specific Devon strategies for managing Long Term / Chronic Conditions such as Chronic Obstructive Pulmonary Disease (COPD), Renal Disease, Coronary Heart Disease, Dementia, Cancer etc.

7. Aims and Objectives of the End of Life Strategy

7.1 **The following aims have been agreed**:

- To bring about a step change in access to high quality care for all people approaching the end of life. This should be irrespective of age, gender, ethnicity, religious belief, disability, sexual orientation, diagnosis or socioeconomic status.
- High quality care should be available wherever the person may be: at home, in a care home, in hospital, in a hospice or elsewhere.
- To enhance choice, quality, equity and value for money

These aims will be achieved through the following:

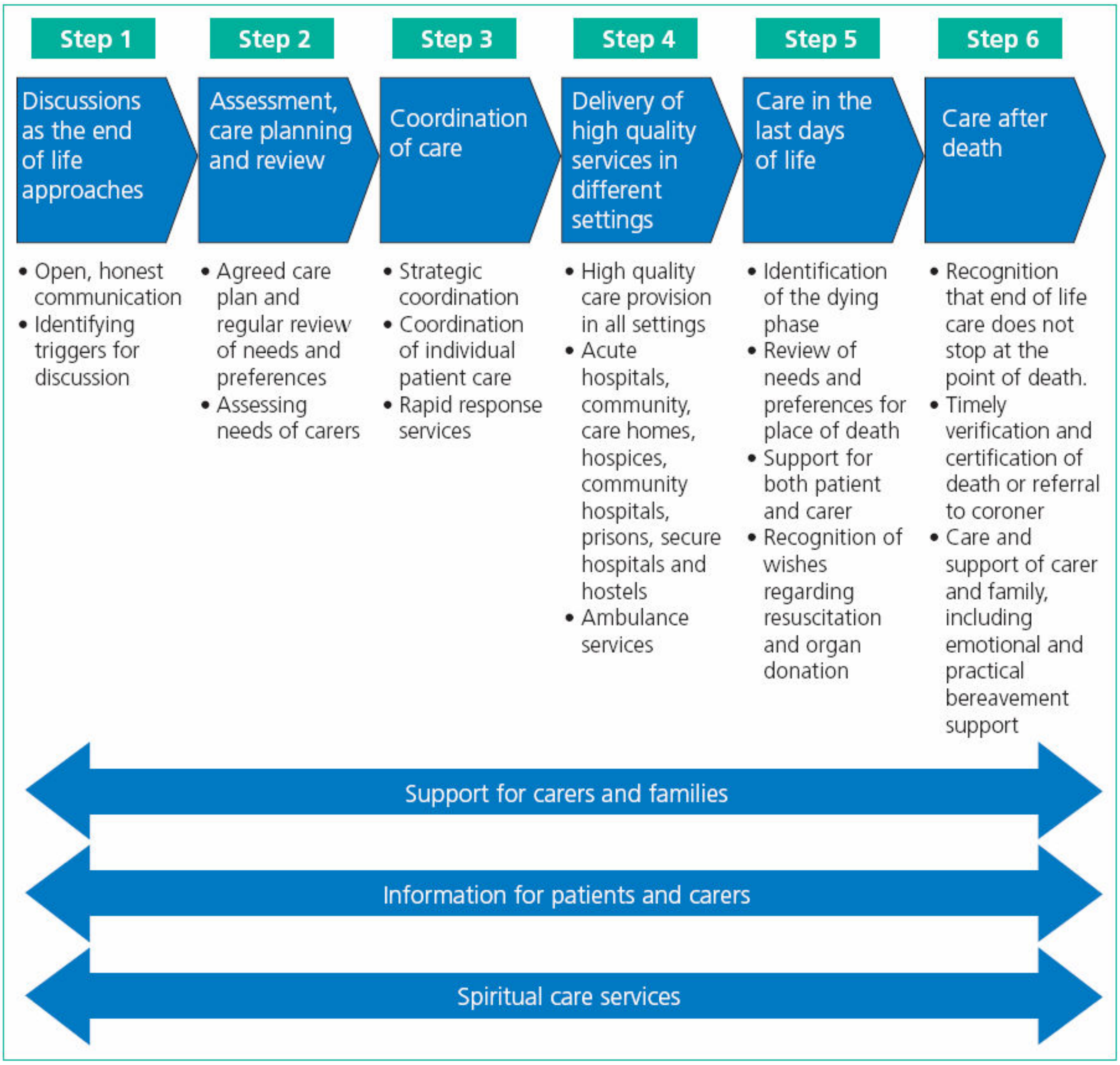
7.2 **Roll out of the Gold Standards Framework** to all practices and for their performance to be equivalent across the Devon health community to the highest level by the end of 2011. This is to be facilitated by the recent appointment of four Macmillan GP GSF Facilitators who commenced work to raise awareness in best practice end of life care with our 107 Devon GPs and 8 GP Consortia across the autumn of 2010.

7.3 **Roll out of the Liverpool Care Pathway and Gold Standards Framework** to all acute trusts, community hospitals, hospices and community nursing teams by the end of 2011. Roll out to all nursing and care homes during 2010-12. This improvement and support is to be facilitated by the appointment of the four Macmillan GP GSF Facilitators and four GSF Care Home Facilitators. The Care Home facilitators will have an educational role to develop Care Champions in care homes to roll out best practice standards and improve Advance Care Planning Training. Their role will run alongside a three year rolling programme of education and training to care home and domiciliary care workers run by the four

Adult Hospices, Devon Care Training and a range of other academic providers, including access to e learning.

7.4 **Care Pathway –** It is proposed that all providers will work to an end of life integrated care pathway developed with the national Map of Medicine team localised to local providers. Care pathways are to be developed in local service redesign / pathway mapping events linked to the four acute providers and four adult hospice communities that service the population of Devon to ensure care is provided as close to home as possible.

The National Strategy identifies the following elements of an end of life care pathway:



Step 1 – Discussions as the end of life approaches
- Open, honest communication
- Identifying triggers for discussion

Step 2 – Assessment, care planning and review
- Agreed care plan and regular review of needs and preferences
- Assessing needs of carers

Step 3 – Coordination of care
- Strategic coordination
- Coordination of individual patient care
- Rapid response services

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, prisons, secure hospitals and hostels
- Ambulance services

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

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

Support for carers and families

Information for patients and carers

Spiritual care services

Source: National End of Life Care Strategy (Department of Health)

8. High Impact Priorities for Improving Quality in End of Life Care

The elements of the care pathway inform the key areas of quality improvement, innovation, productivity, prevention and step change

8.1 Step One – Objective is to identify potential patients and support discussions as the end of life approaches

8.1.1 **Identification of Patients –** using questions, risk stratification, or prognostic indicators, standards and measures for each sector, and across all sectors ensuring all patients who may be believed to be dying within a year should be offered the opportunity to prepare an Advance Care Plan regardless of where the patient is on the care pathway. Assessment can be provided for those in the last year of life regardless of diagnosis, or in some cases in the absence of a diagnosis.

All Devon's GP practices have been targeted to roll out the combined predictive modelling tool to prioritise focus on at risk groups, as well as rolling out the Gold Standards framework GSF.

8.1.2 **Advance Care Plans and Treatment Escalation Plans – Advance Care Plans** developed for all people (as appropriate) and After Death Analysis audit introduced to ensure compliance. This will be a key consideration for planning care packages and avoiding hospital admission where preferred. Treatment escalation plans may be appropriate for some patients.

Subjects for discussion may include the type of care; choice of where people would like to die; preferred priorities for care; funeral arrangements, care of dependents, choice to save others lives in organ donation; how individuals would like to be remembered; whether individuals have particular worries they would like to discuss regarding being ill or dying; what they would like people to know when they die; nomination of Lasting Power of Attorney; loss of Mental Capacity to make choices.

Note: It should be stated that Advance Care plans are a means to an end – not an end in themselves. The important factor is to commence conversations as early as possible and continue until death or loss of capacity.

- **Proposed Action –** To introduce common Advance Care Planning documents, Preferred Priorities of Care documents and Do Not Attempt Resuscitation documents to all NHS, local authority, out of hours and urgent care services and independent sector provider care settings by autumn 2010

- All clinical areas will be encouraged to participate in After Death Analysis

- Advance Care Planning documents already developed to be shared with Devon's Learning Disability team and converted into tools appropriate for this client group with supportive information for carers and families.

- Multi-professional education in advance planning and palliative care will stress the need for end of life care planning to take place early, while someone has sufficient mental capacity and where preferences can be recorded consistent with the principles set out in the Mental Capacity Act. The training will also include pain detection and management for those people who have dementia, recognising that communication problems with this care group may lead to people not being identified as having pain or displaying aggression or confusion.

8.1.3 Palliative and End of Life Care Register - ADASTRA

The effective implementation of Advance Care Planning depends on having systems to identify patients approaching end of life, recording their preferences and making this available across services and agencies 24 hours a day, seven days a week to ensure adherence to the patients preferences. This information will be captured in line with the Gold Standards Framework guidance in Practice Based Care Registers and a new Devon wide Locality Care Register (ADASTRA) based with Devon Doctors Out of Hours Services. This will be available to all stakeholders and supported by two full time register support facilitators 365 days a year.

Proposed Action – The ADASTRA register will ‘go live’ in all NHS Trusts, hospices and general practice across the autumn of 2010. Training for trainers is beginning in all care settings led by the Devon OOH team and the hospices learning and development leads in Advance Planning and Palliative Care.

It is anticipated that all care home providers will also come on line with access to the register during 2011 / 12.

8.2.1 Step Two - Objective is to ensure adequate assessment, care planning and review and assessment of carer needs

8.2.2 General Practice must be signed up to the Gold Standards Framework, have register systems in place to capture this client group, have a named lead for End of Life Care for the practice and a system for reviewing patients with case manager and multi-disciplinary team involvement.

8.2.3 **General Practice** will be supported in identifying patients, improving practice systems, monitoring patients and review by the appointment of GP GSF Facilitators whose purpose is to support education and training and promoting Advance Planning and After Death Analysis.

8.2.4 Whilst originally developed for GP’s, the GSF framework is now being rolled out to all medical specialisms with support and development from Specialist Palliative Care Consultants and with GPs advising on education and Advance Planning.

8.2.5 **District Nurse –** teams have a consistent approach to all people with end stage disease, identified via the Devon Locality Palliative and End of Life Care register and hospital discharge teams

8.2.6 **Holistic Assessment –** and service delivery across all sectors (including SAP/ESAP –single assessment programme)

8.2.7 **Recognition of Spiritual / Religious Needs –** evidence suggests spiritual needs which include beliefs or practices associated with religion, faith or culture are often not recognised by health and social care professionals in care assessment and care planning of individuals. Carers and relatives are often not assessed and many health and social care professionals lack confidence in this area. There is no commonly accepted definition of spiritual support and services are often provided through chaplaincy in the hospitals and hospices, but less is known about what models of spiritual support might look like in community settings, including care homes. This has become a national priority for action and the National Council for Palliative Care is working with Health and Social Care to devise a common framework with practical guidance and assessment tools

Access to spiritual assessment must be considered as part of Advance Planning conversations with people and their families and carers. Spiritual needs may include the need to be loved, maintaining self esteem, dignity, integrity, identity, value and worth, hope, freedom, self-expression, community, fulfilling relationships, creativity, contribution and rest.

These are difficult subjects to discuss with people with palliative care needs and communication and listening are key skills for all care workers.

- **Proposed Action** – There is a need for faith leaders, users and health and social care professionals to develop a common Devon Spiritual Assessment tool which can be used in all care domains. What we seek to achieve here is personalised care, in a culture of the tick box. There is a need to help people who may have no faith or religious affiliation.

- Ensure continued access to basic Communication Skills and Advanced Communication Skills training for all health and care workers depending on their level of work and competence.

8.2.8 **Carer Support –** ensuring carers assessments are undertaken and support is offered through access to good carer information accessible in a variety of formats and languages

8.2.9 **Support to Care Homes –** NHS Devon is working with the four hospices, four GSF Care Home Facilitators and four GP GSF Facilitators to facilitate education and training in advanced care planning and palliative care management. This will ensure that providers feel more confident and therefore avoid sending care home residents into hospital to die when this may not be the person's choice.

8.3 Step Three - Objective is to ensure strategic co-ordination of care

8.3.1 **Strategic Co-ordination - Single Point Access Helpline** – the proposal is to introduce a nationally recognised 'three digit telephone number to act as a single point access for all individuals and agencies to call in an emergency. As well as developing joint information and technology links between out of hours and ambulance services by the end of 2010.

8.3.2 **Communication –** which should be kept as simple as possible and is high quality across all sectors. Access to a single point of contact for co-ordinated 24 hour care services for people approaching the end of life with services developed at a locality level.

8.3.3 **Co-ordination of individual patient care - Key Worker Care Co-ordination** based in primary, secondary or social care, with nominated liaison in other areas as required. Named key workers for each part of the patient's pathway documented within the Devon Locality Palliative and End of Life Care Register and person's Advance Care Plan. Specialist Palliative Care Community Nurses, District Nurses, GPs and members of the Complex Care teams are seen as the key workers and core team in primary care settings. Hospital medical and Ward and Clinical Nurse Specialists are seen as key workers in acute care settings. These key workers should be made known to people receiving services.

8.3.4 **Equity in Out of Hours Care with availability of 24/7 Community Nursing / Domiciliary Support** to include access to equipment, OOH Just in Case medicines by the end of 2010. This will see the introduction of OOH nursing and Domiciliary Care multi-disciplinary teams aligned to emergency services across Devon 24hrs a day. This service collaborative as well as personal care services from the independent sector will be delivered by skilled, trained and competent staff working under clinical supervision, (including Marie Curie and Hospice staff) will facilitate support to enable people to be managed closer to home and prevent urgent care admissions to hospital where possible. Just in Case medicines will be made available to all people identified as being identified in the final days of life.

Proposed Action – OOH Nursing and Domiciliary Care will be rolled out across the whole of Devon during November 2010. Just in Case Medicines will also be introduced at the same time.

8.3.5 **Rapid Response Services** – these include linking access to 24hr specialist medical on-call advice from the four Devon Hospices, into the new Devon Referral Management Centre run by South West Country Ambulance services.

8.3.6 **Rapid Response Services** – introduction of a Devon Directory of Bereavement Services to be held by the Devon Referral Management Centre who can signpost people into bereavement services when and if appropriate.

8.3.7 **Equipment Access –** ensuring that key pieces of equipment are readily available e.g. syringe drivers, hi-low beds etc

8.3.8 **Fast Track Continuing Health Care (CHC) Pathway –** This is used to gain immediate access to NHS Continuing Healthcare funding where an individual needs an urgent package of care / support and their condition is rapidly deteriorating and / or entering the terminal stages. The assessment tool is linked to the Gold Standards Framework and Liverpool Care Pathway and must be considered in line with the Mental Capacity Act where appropriate.

8.4 Step Four Objective – Ensure delivery of high quality services in different settings

Individuals, families and carers may require services provided across a number of different settings and by a number of different providers. There is an intention to ensure all the services are informed by the following:

8.4.1 **Evidence Based Practice & Clinical Guidelines –** palliative care services are informed by evidence based practice and delivered to meet the needs of those with general and specialist palliative care needs as per NSF, NICE Guidance and the NHS Cancer Standards

8.4.2 **Service Monitoring and Review** – to ensure that services provided which can be reviewed to ensure the most cost – effective and efficient, peer reviewed and models compliant with NICE guidance are adopted in each locality

8.4.3 **Learning from Complaints and Significant Events –** utilising learning from complaints and significant events to inform changes in policy and practice and prevent reoccurrence

8.4.4 **Review and Improve Access to Psychological Support Services –** establish links with community mental health teams- Community Psychiatric Nurses, graduate workers, Talking Therapies development (CBT) to develop supervision and support for nurses and other professionals. Working across psychological therapy providers to develop a psychological assessment tool for sign posting people into the appropriate professional advice.

8.4.5 **Pain Management –** access to pain management specialist teams in community settings

8.4.6 **Respite Care –** access to respite care and protected beds in community hospitals / nursing homes for palliative / end of life care thus avoiding admission to acute hospitals where possible

8.4.7 **Access to Complementary Therapies –** access to a range of complimentary therapies for palliative care / end of life patients

8.4.8 **Development of Community Nurse Specialists in Renal Services** – to support GSF roll out and advance care planning into renal units and satellite dialysis units in Devon in line with national guidance and the Renal NSF. Plymouth Hospitals Trusts and the Royal Devon and Exeter Hospital will access the ADASTRA for all renal patients on dialysis or failing transplant; it is estimated that there may be over 200 patients in each unit. These new roles will act as the liaison point between primary and secondary care and will work in collaboration with specialist palliative care teams and GPs.

8.5. Step Five – improving the last days of life

Identifying people in the last days of life is challenging, but, in the context of a deteriorating or progressive life-limiting illness we would expect all providers to have systems in place to ensure:

- People are placed on the Liverpool Care Pathway where appropriate
- Health and Social Care professionals are aware of Advance Care Plans and can access the Devon Locality Palliative and End of Life Care Register ADASTRA
- Devon wide ‘Do Not Attempt Resuscitation’ (DNAR) decisions are communicated and made transparent for all agencies including OOH and Emergency Services. These will be held in care settings and upon the End of Life Register.
- Access to anticipatory ‘Just in Case’ medicines to be introduced across Devon in November 2010
- People and their families are offered psychological and spiritual care following assessment
- Care for the partners, carers and families before (pre bereavement) and after a person’s death (post bereavement)
- Wishes regarding organ and tissue donation are documented and available on the End of Life Register

8.6 Step Six – the objective is to ensure a ‘Good’ end of life care does not stop at death

8.6.1 **Death Certification is changing** by the introduction of a single unified system for both burials and cremations by the appointment of medical examiners to provide independent scrutiny of the cause of death. These changes will simplify and strengthen current arrangements, improve the quality and accuracy of data on the cause of death and increase transparency for bereaved families.

This independent scrutiny will be carried out by the new proposed Devon medical examiners and will replace the secondary certification currently provided by doctors for cremations and will reduce delays. Not all deaths will be referred to the coroner, however the new posts will have a key role in working with GP consortia and local scrutiny boards to establish whether there are clusters or patterns of deaths in the Devon community which give any cause for concern. NHS Devon is proposing to introduce special training for this key role.

8.6.2 **Access to Bereavement Services –** National and local evidence suggests a neglect of bereavement services by health services. There appears to be a lack of knowledge of how to access services. Many services may not be well known or co-ordinated and over 80% are offered through the independent and voluntary sectors. Services are often not offered by health professionals to older people and may be confined to those individuals who are known to services whilst a deceased person was alive.

Research suggests the effects of grief can be:

- traumatic and stressful
- impact upon physical and mental wellbeing can create social upheaval
- interpersonal and role changes
- income and support network changes
- lead to health threatening behaviour i.e. increased alcohol and drug abuse

Grief may be magnified in later life due to bereavement plus complexities of ageing, changes in social roles, changes in residential environments, poor family or friendship support and loneliness for those living alone.

NHS Devon and Devon County Council wish to ensure all people are supported to have their Pre-Bereavement and Post Bereavement

- Needs assessed
- Have access to high quality information
- Receive respect, recognition and informed consideration
- Have access to, and are provided with, information of appropriate services and support

❖ **Proposed Action** - In order to achieve this NHS Devon is working with statutory agencies and the third sector to develop an electronic directory of Bereavement Services with hard copy documents to be held in doctors' surgeries, libraries, information centres, public access points.

❖ It is intended to develop a commissioning specification for Bereavement services developed in collaboration with a multi-agency peer reference group including voluntary agencies such as CRUSE during 2011. CRUSE for example, has considerable experience at providing services to people with different needs and have experience at helping those with Learning Disabilities.

❖ Need for the development of Bereavement Befriending services across Devon, distinct from counselling roles where there is potential for market development of this type of approach from the voluntary sector

9. Supportive Strategies for Quality Improvement

9.1 'Individuals, patients and carers are always the priority'

Improvements need to be sector specific, but linked through common pathways, with individuals, patients and carers always the priority. NHS Devon and Devon County Council will continue to develop co-ordinated strategic plans relating to sustainable services and organisations. These include:

- Commissioning pathways which will ENABLE CHOICE and BEST PRACTICE in end of life care for all
- A Workforce Strategy which incorporates succession planning ensuring that staff have access to HIGH QUALITY SKILLS, KNOWLEDGE, TRAINING and GOOD QUALITY SUPERVISION & APPRAISAL for the benefit of individuals, patients and professionals
- Development of an NHS Devon and Devon County Council community public information programme to RAISE AWARENESS of the issues.
- The sector specific service improvements which need to take place, HOW we implement them, WHO implements them and how these are monitored
- STRENGTHENING COLLABORATIVE WORKING PARTNERSHIPS with statutory, voluntary and independent providers, facilitating the development of new provider models such as Social Enterprise partnerships and promoting quality, innovation, productivity and prevention.
- Exploring the use of POOLED BUDGETS with LOCAL STRATEGIC PARTNERS – to support health and social care workforce planning and the development of integrated teams
- A VOLUNTARY SECTOR SUPPORT SYSTEM – development of patient, carer, volunteer training and education through working with the third sector to make improvements and developing the use of the Third Sector Compact Contract
- ACCESS TO HOUSING & FINANCIAL BENEFIT ADVICE **–** advice and support will be made available both in hospital and community settings as a point of contact
- CARER SUPPORT - Devon has a high number of carers (approximately 73,000), and work to support them is outlined within the Devon Carer Strategy. Key developments include ensuring carers' needs are assessed and recorded in the ADASTRA EOL Register over time and that carers have access to health and well being checks and carers breaks.

9.2 User Feedback

PALs Services across NHS Devon reviewed all their case referrals for 2009/10 in relation to concerns about end of life care in hospitals and community settings.

The concerns have been used to inform the development of the Strategy and have improved the development of the plans to improve services within it.

Key concerns raised were around:

- The need for information on how to arrange a funeral
- Help and advice and someone to turn to after hearing an individual has been given a terminal diagnosis – Breaking Bad News
- Advice on advance care planning and wills
- Advice on autopsy and the role of the coroner
- Upset and insufficient follow up and support after a sudden death for family members
- Dignity and respect in the treatment of the body
- Understanding probate
- Rights for separated families
- A need for improved access and signposting into Bereavement Services

10. Workforce Development

10.1 NHS Devon and Devon County Council are committed to the development of an integrated, cross agency, cross-professional workforce development plan, linked to local and national training and development frameworks to ensure the workforce are equipped to develop and deliver the needs of the local population.

10.2 Medical, nursing and allied health professionals working in palliative care have a combined need to maintain their own Continuous Professional Development whilst training other members of staff. GSF Facilitators and specialist nurses and clinicians have a key role to play in rolling out the GSF, advance planning and predictive modelling.

10.3 Devon Doctors OOH Service is the training provider for the ADASTRA register and is currently rolling out training for trainer sessions.

10.4 Key priorities for delivery by providers are: Advance Care Planning; Symptom Control; Syringe Driver Management; Anticipatory Prescribing; Improved Co-ordination and Better Hospital Discharge; Special Message Handling; Death Certification; Bereavement and Dealing with Loss; Advance Communication Skills, Communications Skills and Breaking Bad News Training; Supporting Carers; Implementation of the Palliative Care and End of Life Care Register; Training in Care Homes and training for domiciliary care workers.

10.5 This work is underpinned by academic programmes in palliative care and end of life care offered by a range of providers at undergraduate and graduate level; there is also considerable work being undertaken by a number of third sector agencies in educating volunteers. All four adult hospices are pivotal in delivering many of the programmes.

10.6 As well as academic providers, the Department of Health End of Life Care team offers a wide range of educational resources accessible via the department of health website. These include access to End of Life E-learning modules which are a valuable resource for health and social care professionals in all care domains.

10.7 Engagement with Care Home and Domiciliary Care providers in Devon is providing a huge educational challenge for the statutory agencies. NHS Devon and Devon Care Training have agreed to pool budgets and work with the employers of approximately 11,500 care home staff and 12,000 domiciliary care workers to ensure access to:

- Tailored Classroom teaching if required
- In-house training sessions – delivered in groups or one-to-one
- Access to E-Learning

Proposed Action

- Develop an Educational Pack for Care Home and Domiciliary Care Managers.

- Work with colleges and the Dying Matters Coalition to develop a training DVD and CD Rom with worksheets and audit tool for staff.

11. Research and Development

NHS Devon and Devon County Council are keen to support the development of evidence based practice in all aspects of palliative and End of Life Care, as well as developing an understanding of the societal attitudes and behaviours towards death, dying and bereavement. Feedback from users and carers are of particular importance to organisations in influencing change.

Proposed Action

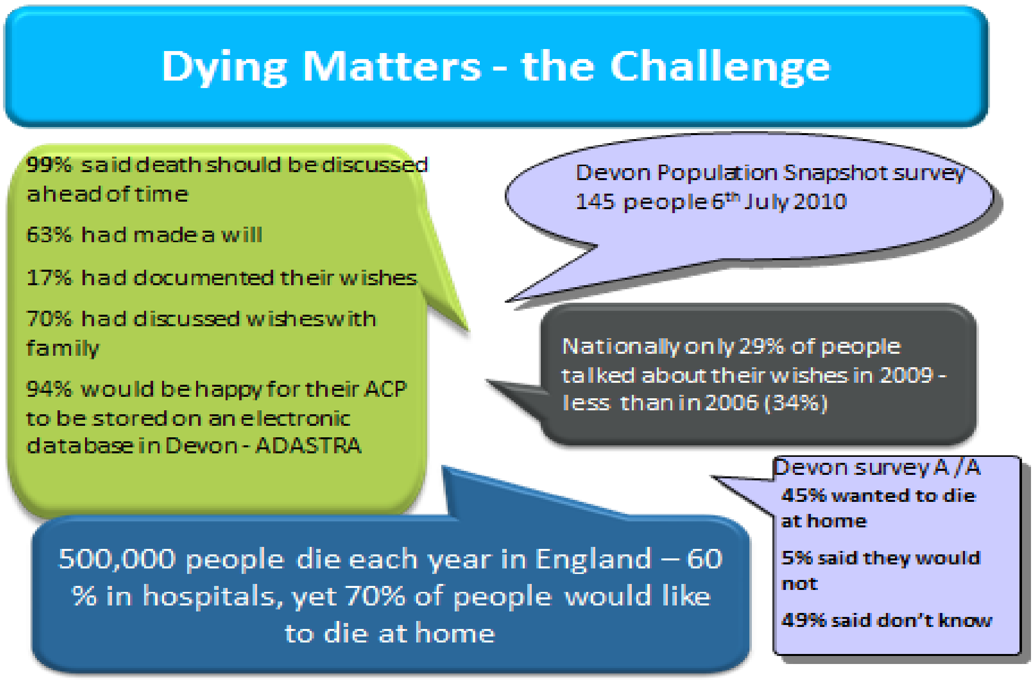
- To set up a research network for End of Life Care accountable to the Devon End of Life Strategic Commissioning Group. This will be chaired by a Public Health Consultant and will feed into work of the Peninsula Medical School and University Health and Social Care Research faculties.

12. Developing a Public Campaign to Live Well to the End of Life

12.1 Many consider death to be the last taboo in our society and many find it difficult to engage in advance with services about the way in which we would like to be cared for at the end of life. Many do not talk about dying and death, but if more people had their needs and choices met, more would campaign for sustained improvement.

12.2 NHS Devon and Devon County Council are working with the Dying Matters Coalition spearheaded by the National Council for Palliative Care. Their research in 2009 indicated 29% of people talked about their death and dying wishes and 54% of complaints in acute hospitals were associated with care of the dying. There are gender differences between men and women associated with discussing these topics and there is a need for taking different approaches for different groups. Communication was key, and GPs and Community Champions in End of Life Care were highly valued in the research. The introduction of Advance Care Planning will be enhanced by combining this with a public campaign on raising awareness of death, dying and bereavement

12.3 The partnership ran a Dying Matters Conference for 150 delegates during July 2010. Using interactive voting and work from the national Dying Matters Coalition a survey was completed which revealed the following feedback.



Dying Matters - the Challenge

99% said death should be discussed ahead of time

63% had made a will

17% had documented their wishes

70% had discussed wishes with family

94% would be happy for their ACP to be stored on an electronic database in Devon - ADASTRA

Devon Population Snapshot survey 145 people 6th July 2010

Nationally only 29% of people talked about their wishes in 2009 - less than in 2006 (34%)

Devon survey A/A

45% wanted to die at home

5% said they would not

49% said don't know

500,000 people die each year in England – 60 % in hospitals, yet 70% of people would like to die at home

12.4 The conference feedback also revealed that the Devon community valued:

- hearing about individual's personal experiences
- the ideas about Advance Planning and the Mental Capacity Act
- the opportunities to network and discuss complex issues
- the services we already have in place
- good liaison between different agencies work now – long overdue
- the potential to develop the North East Good Death Charter to a local model

- the need to run a public awareness campaign across Devon and break down barriers
- the need for more cross agency, cross border working
- the opportunities to shape future education to local needs
- the importance of getting peoples wishes right and the difficulty this poses
- the benefits to professionals and the public if we break down the taboos of death and dying
- input from the Dying Matters National team and their support tools

12.5 Everyone has a right to a good death, and family, partners and other carers deserve support and compassion. When promoting health and well being, NHS Devon and Devon County Council have made a commitment to establish a public health charter for a good death which relates not only to medical and nursing care, but to the behaviour of all agencies, sectors and communities who deal with these issues.

12.2 It is our proposal to develop an organisational and public awareness and social marketing campaign building on exemplar work undertaken by, and in collaboration with the NHS North East Strategic Health Authority and the National Palliative Care Council – Dying Matters Coalition. It is intended to work together with the NHS South West Strategic Health Authority and the South West Regional Public Health Observatory to share the public health charter developed in the North East with members of the public and organisations in the Autumn of 2010 encouraging them to make a real contribution to informing the scope, content and tone of an End of Life Charter for Devon.

12.3 Devon is seen as a national beacon site for End of Life Care and is part of a national pilot site for community development which it is hoped will be led through the Public Health Improvement / Community Development Leads, local hospices and general practice during 2011.

12.3 The NHS Devon and Devon County Council End of Life Strategy, and the Devon public and organisational awareness campaign will continue to be championed in a second Dying Matters Conference focusing on Community Development to be held at the Cuthbert Conference Centre at Buckfast Abbey in Devon on 2nd November 2010. The aim will be to support four overarching themes to improve end of life care. These are:

- ❖ To engage wider Devon society through a public health approach
- ❖ To make best practice consistent across the county
- ❖ To develop staff in delivering high quality evidence based care
- ❖ To ensure planning, commissioning and delivery of care is better integrated in the delivery of seamless care

12.4 Smaller ‘Dying Matters’ events are being proposed at a locality level looking at a variety of ways of engaging the public in the debate. These include workshops, coffee mornings, forum meetings and the potential development of a Devon wide Retirement Pack including Advance Planning tools.

12.5 The key commitments to our Devon population are to establish core standards and commissioning expectations for all health and social services supporting those at the end of life.

- We will ensure that all individuals and their families will receive the same standards of care in all settings, wherever their choice of place of death where appropriate.
- We will ensure that the full ranges of services to support the end of life are available, tailored to individual needs. The commissioning and provision of these services will be built around supporting the Gold Standards Framework End of Life model.
- Resources will be utilised to more effectively support individuals at the end of their life and through flexible use of these resources, led by individual preferences, nature and location of support.

12.6 The charter will:-

1. Have a statement of the rights and entitlements that should be honoured both for the individual preparing for death, and for their carers and families.
2. Extend beyond medical and nursing care to include agreement between providers of health and social care specifying the level of public sector funding that should be appropriate in support of terminal care services
3. Support and promote the national standards of training and education of all staff who deal with end of life and bereavement
4. Define entitlement to bereavement support and counselling to ensure meeting the ongoing needs of this vulnerable client group
5. Seek to address Equality and Diversity issues by engaging with a range of minority and hard to reach groups including learning disability clients, BME groups, travellers, etc
6. Use a variety of consultation mechanisms including focus groups, telephone interviews, web based feedback and community development workers in localities
7. Build upon the work undertaken by NHS North East following consultation in Devon with public and partners to develop a localised model

See attached draft Charter (Appendix 1)

12.7 Discussions about the Devon End of Life Care Strategy, the draft Charter and the agreement of priorities requires consultation. We would anticipate this to be 3 months from November 2010. This will raise the profile of the subject and enable discussion with local groups such as funeral directors, crematoria, religious organisations, solicitors, community groups and schools.

13. Awareness Raising in the Statutory Agencies, Independent Sector, Business, Retail, Manufacturing, Banking, Tourism, Agricultural Working, Public Sector

- **Raised Awareness –** of the issues of caring for relatives or friends at the end of life
- Recommending employers implement **Carer Support** strategies and develop **Compassionate Human Resource Strategies**
- Providing support on knowing how to **Support Employees** who have a life which is imminently limited by illness e.g. help with benefits, statutory and company support
- Encouraging **Staff** to volunteer out of work, even if it's a few hours a month
- **Fund Raising** for a chosen charity or local voluntary sector organisation

14. Awareness Raising in Education – Schools and Universities

- Raised awareness of the issues of **Children / Students** with life limiting disease
- Learning as an organisation how to support the child and the **family**
- Learning as an organisation how to support children / students who are **carers**
- Learning as an organisation how to support children / students who have a **dying parent or family member**
- The school / university developing a relationship with the local hospices and third sector providers, and knowing who to ask for help with bereavement **counselling**
- The school knowing how to support a family where **child care** may be erratic due to the death of a parent
- Providing **information, education and advice** to young people's curriculum 14 – 19yr olds in Devon schools

15. Working with Faith Groups, Churches & Spiritual Centres

- Helping to support communities in the **understanding** of the issues surrounding death and dying
- Helping support **access** to support services
- Supporting **volunteer** development within local religious and spiritual communities
- Examining new ways to help patients and carers who may be experiencing **isolation** and loneliness
- Ensuring services **support** those with no faith denomination
- Developing a Devon wide **spiritual assessment tool**

16. Working in Prisons

- Helping to support prison communities in the **understanding** of the issues surrounding death and dying
- Helping support **access** to adequate specialist medical, nursing and support services
- Examining new ways to help prisoners who may be experiencing **isolation** and loneliness

17. Working with Community Organisations

- Developing a **Support Base** within the community to encourage well being centres and agencies to support people to self care, and care for each other.
- Developing a **Volunteer Workforce**
- Developing **Community development worker roles** to support consultation on improved end of life care
- **Fund Raising** for chosen local charities

18. Working with the Armed Forces, dependents and veterans

- Helping to support Armed Forces and 'veterans' groups in the **understanding** of the issues surrounding death and dying
- Helping support **access** to adequate medical, nursing and support services
- Raising awareness for veterans' charities and associations in supporting and delivering **information and care** to veterans, dependents and carers
- Examining new ways to help armed forces veterans who may be experiencing **isolation** and loneliness
- Linking Armed Forces and veterans national policies to the **local delivery** of medical, mental health and end of life care strategies.

19. Access to Social Care

- **Carers** are offered **assessment** and support
- Access to **respite care / short breaks** for carers
- Provision of meals and **access to adequate nutrition** where needed
- Access to a wide range of **housing and support solutions**
- **Easy access to benefits advice**, power of attorney, mental capacity advice
- **Advocacy Services**
- **End of Life Champions** established in social care teams

20. Partnerships

20.1 The strength of the partnerships and collaborative working across Devon will be the basis for the successful implementation of the strategy.

20.2 **Practice Based Commissioning (PBC) and GP Consortia** - The recent White Paper has placed the responsibility for commissioning many end of life services in the future with GPs and GP consortia. In Devon we will drive improvement in End of Life Care through the new locality structures. Clinical engagement is integral to the development of new care pathways, particularly in the context of providing local community based options for end of life care, and reducing acute admissions leading up to and at the end of life. NHS Devon and its GP Consortia are required to deliver a 30% reduction in acute admissions by 2012, for which local delivery of the objectives in the end of life strategy will be key.

**** Needs a paragraph on GPs as providers (JW)****

20.3 **Local Area Agreement** (LAA) - The approach to end of life care set out in the strategy is based on partnership working, personalised healthcare for end of life care cannot be delivered without close working with the local authority and other partners. The Local Area Agreement enables NHS Devon, Devon Council and their partners to plan and act collaboratively. This mechanism will ensure stakeholder support for the end of life care strategic priorities. The ambitions for Devon set out in the LAA show the commitment by organisations in the county to work in partnership to achieve improvements for people, supporting people to have independent lives and to make informed choices about their long term health and well being.

20.4 **Service Providers** – Constructive relationships with all the providers of end of life care (hospices, NHS and social care community providers and acute trusts) are critically important to delivering the strategy. The introduction of locality neighborhood teams by Devon Community Provider Services, the PCT's arms length provider arm, has provided access for people nearing the end of life to integrated health and social care services. Community teams ensure that there is a pro-active programme of care for patients at the end of their life. The programmes are built around the Liverpool Care Planning Pathway and the Gold Standards Framework.

20.5 **Leadership** – The NHS Devon Board, through the End of Life Strategic Commissioning Group, leads the development and implementation of the Devon End of Life Strategy. They have a pivotal role in influencing and the equipping of local services to deal effectively with future challenges. Localities and GP leadership will be critical to the sustainability of these changes.

20.6 NHS Devon has established a provider forum for all five hospices to come together to share learning and explore new opportunities offered by the Transforming Community Services agenda. The forum will also focus on need, commissioning of End of Life care and the development of contractual models.

21. Strengthening Commissioning

21.1 NHS Devon and Devon County Council Commissioning teams have a **portfolio of powers to improve delivery of integrated health and social care services**. These include utilising their joint commissioning powers, promoting choice, developing providers, improving system management and regulation and using tariff and incentives to influence change.

21.2 **Reforming Provision** – NHS Devon and Devon County Council have the freedom to encourage new providers into the market who are prepared to work within new style collaborative working models around delivering end of life care. Working with existing service providers will be focused on improving quality and ensuring value for money.

21.3 **Improving Quality, Effectiveness and Efficiency** – The Care Quality Commission measures minimum standards of quality for all health and social care providers. The national End of Life Quality Markers were published in June 2009 and these have been used by the NHS along with national NICE best practice guidance, to inform the 2010 / 11 NHS and third sector Contracts and future Quality Accounts. The health community has also participated in national After Death Analysis work. This will be more effectively facilitated in the future by the introduction of the new electronic End of Life register

21.4 **Increasing Choice and Personal Focus** – choice and competition will challenge existing providers of care to improve their responsiveness and make improvements in end of life care. The ability to capture advance decisions and wishes and preferred priorities of care will create a shift in care from acute providers to care arrangements closer to home.

21.5 **Responsiveness** – NHS Devon and Devon County Council gathers feedback on an annual basis from patients, the public and providers of end of life care. Programme management and budgeting showing benchmarking, health community spend and outcomes will be evidenced in the future to demonstrate transparency.

21.6 **Map of Medicine Integrated Care Pathway for End of Life Care** – the Map of Medicine contains a national knowledge base of best practice, building on excellent work in South Devon Healthcare Community with the Right TRAC Programme. NHS Devon will seek to involve clinicians, patients and other agencies to develop a localised End of Life Care Pathway to shape local delivery of end of life care, add specificity of local processes and demonstrate outcomes. In the absence of a national tariff, these pathways can then be costed and local tariffs developed for End of Life Care.

21.7 **Medicines Management** – End of Life Care consumes significant pharmaceutical resources and due to the nature of the types of drugs used there is always the risk of misuse. Clinical audit and a dedicated pharmaceutical adviser has been made available to support commissioning of End of Life Care to mitigate the risk, to work with clinicians on monitoring outcomes and horizon scan new drugs and therapies.

21.8 **Best Value Within Resources** – The End of Life Strategy provides an opportunity for Practice Based Commissioners, GPs and primary care to create more appropriate non hospital based models of care for end of life patients. Patient Choice may also drive this change of practice. It has to be recognised however that the Devon population demographics may see many people still wishing to die in a hospital bed particularly a community hospital bed.

21.9 **Improved Procurement and Contracting** – NHS Devon has strengthened its operating plan and business rules for 2010/11 to ensure long term sustainability of existing services. A revised Contestability Framework describes the way in which NHS Devon intends to approach securing future providers of health services for the population it serves through tendering in an open market context. This is to maximise the benefits of value for money, quality and choice, control of demand, responsiveness, equity and resilience through a range of procurement / commissioning models that best meets the palliative care needs of the population.

21.10 Through engagement with all our partner organisations providing palliative and end of life care we are working hard to ensure more suitable, robust and applicable contracts for 2011/12. Where applicable, our contracts with the charitable and third sector will be for 3 year periods to provide long term stability, and will develop to meet the NHS Devon Quality, Innovation, Prevention and Productivity agenda.

21.11 **Finance and Programme Budgeting –** NHS funding streams for end of life are complex and difficult to quantify. Finance teams have been working to develop a single point access Programme Budget for End of Life Care this year to attempt to bring together budget lines of spend into one programme budget. The projected spend for 2010 is:

Analysis of Estimated Spend 2010/11 - End of Life	**Total Spend £000**	**% of spend**
Training & raising awareness (incl facilitators)	285	1%
Development of locality register	81	0%
Rapid response/24 hour community services	498	1%
Other community services	1,980	6%
Support for voluntary hospices	3,434	10%
Support for Marie Curie nurses or equivalent	290	1%
Hospital based care (incl Community Hospitals)	10,971	33%
Other locations	16,085	48%
Other	25	0%

33,648	100%

21.12 **Funding Arrangements** – Social care funding arrangements for an individual's care is often highly complex; in particular, the differing entitlements of people who are wholly or partly self- funded. In the past inflexible budgets have resulted in a lack of continuity and fragmentation of care, and individuals and families have often found it difficult to navigate the system, which can be distressing for individuals at the end of life and their carers.

21.13 Self-directed and person centred care – Personalisation (understood in its broadest sense of promoting self-directed care and informed choice), use of personal budgets where available, and re-ablement initiatives present an opportunity to develop flexible, improved user-led packages of care which may be more appropriate to the user and more cost effective.

22. Outcomes and Performance Framework

22.1 NHS Devon and Devon County Council are committed to achieving improvements in End of Life Care. The principle health outcome the organisations would wish to aspire to is an increase in the number of deaths which take place at home, where that is the person's choice of place, from 24 % currently to meet the targets set out below.

2010 / 11	2011 / 2012	2012 / 13	2013 / 2014	2014/2015
30%	35%	41%	49%	56%

Note: Nursing Homes and Care Homes are people's homes in many circumstances

22.2 Progress against the range of initiatives described in Section 8 will be monitored by the NHS Devon Board, the NHS South West Strategic Health Authority and the relevant health and social care partnerships in the health community.

22.3 Reporting will be monitored through
- Hospital Episode Statistics
- Public Health Data sources – South West Public Health Observatory EOL Intelligence Data
- Practice Quality and Outcomes Framework Data
- After Death Analysis Reports generated from the Devon Locality End of Life Register (ADASTRA)
- Contract and Quality Monitoring
- Complaints and significant events

23. Next Steps

23.1 The End of Life Care strategy has a number of work plans which underpin the strategy which sets out the tasks to achieve targets and outcomes. Many of the outcomes will be delivered by frontline teams in the community, working with professional colleagues in primary care, social care, the independent and voluntary sectors, care homes and hospices. The main means of delivery will be through the Gold Standards Framework, the Liverpool Care Pathway and the Preferred Priorities for Care.

23.2 A key role of the Devon EOL Strategic Commissioning Group will be to support delivery of the End of Life Strategy in driving innovation and development of services and care pathways in collaboration with Practice Based Commissioning Consortia, Devon provider services, GSF Facilitators, Devon County Council and other partners and stakeholders.

23.3 Views of all stakeholders and the public will be used to inform the strategy and reflect the issues. The strategy will be launched for consultation following sign off by the Executive teams of NHS Devon and Devon County Council during October 2010

To add Appendices

1. Membership of the Devon EOL SCG
2. EOL Care Frameworks and Pathways – LCP, GSF,
3. Pathways for Palliative Care, Urgent Care, Specialist Palliative Care
4. Draft Devon EOL Charter
5. NHS Devon EOL New Spend
6. Bibliography

Appendix 4

A good death

Time to Think

Draft DEVON CHARTER

COMPASSION AT THE END OF LIFE

All of us should have the right at the end of life to experience a good death and our family, partners or other carers deserve support and compassion at this time.

Sensitive and appropriate end of life care support should begin at the time illness is identified and continue throughout ill health, during death and in bereavement. It should be available to people coming to the end of life at any age and from any condition.

This charter will guide health, social care, community, voluntary and other organizations, groups or individuals who plan, develop and provide end of life care and support. It will help to ensure the right services are available at the right time for individuals who are dying, their families and carers.

All care providers should be aware of the charter, and its impact on their work, not only those who work specifically in end of life services.

Principles of a good death

Respect:

- To see death acknowledged as part of life
- To be treated with dignity, respect and privacy, according to our wishes
- To be supported and cared for in a positive and enabling atmosphere, in a way which values each individual and the contribution we may still wish to make to our family, job or social network
- To have clear, honest and tailored information and good communication throughout illness or frailty

Time to plan:

- To be told clearly and compassionately the reality that death is coming.
- To be provided, where possible with a realistic prediction about how long illness may last, and information about what can be expected, to allow time to plan
- To be given the opportunity to make a plan for our care in advance which takes account of our wishes and to have that respected by health and social care services

Care:

- To have access to end of life care in the location we choose, with every effort made to support this
- To have a named key worker who will organize and co-ordinate care, including where this cuts across organisational boundaries.
- To have clear information about whom to contact around the clock and seven days a week if advice or care is needed at home
- To be given every opportunity to take part in decisions which effect care. If the person who is dying is unable to do this then the views of people close to them must be taken into account
- To receive speedy, practical help for the end of life
- To receive the best care and support with any social difficulties
- To have help to control physical pain and to alleviate emotional distress, if they occur.

Support:

- To have support with the practicalities of dying, death and matters after death
- To receive appropriate emotional or spiritual support, with our beliefs and values honoured
- To have access to appropriate specialist support, including counseling if required, for families, partners, carers and staff. This may be before or after death occurs.

This charter was developed in partnership across health, social care and other organisations across the north east of England, and with the involvement of patients, carers and their representatives.

It is our proposal to update and amend this to take account of the views expressed by members of the public and professionals during a consultation exercise which will run between August and the end of December 2010