NORTHUMBERLAND COUNTY COUNCIL

CARE AND WELLBEING OVERVIEW AND SCRUTINY COMMITTEE

END OF LIFE CARE WORKING GROUP

May 2012

"The north east is the first area in the UK to adopt a broad-based public health approach to end of life issues. The principles of respect, time to plan, care and support set out in our charter for A Good Death are central to our vision of ensuring the best possible experience of death, dying and bereavement for all." Good Death Advisory Group 2012

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Places of Death

Principles of the "Good Death" Charter

END OF LIFE CARE IN NORTHUMBERLAND

Executive Summary

During discussions to agree a scrutiny work programme, End of Life Care in Northumberland, was identified as an area in need of development and improvement. This, allied with the higher national profile afforded to End of Life by the publication of the first national strategy, led to the establishment of the Working Group.

End of life care is an emotive and sensitive topic to consider. Death and how society cares for the dying remains, to some extent, a taboo topic that people do not wish to speak about. Often the view is that to speak about it is somewhat morbid and macabre.

However, we live in a time when around 60% of deaths could be considered to be predictable or expected, following illness or frailty. We also live in a time when the proportion of older people in the population is increasing, and death becomes more likely the older one becomes.

The Working Group has gathered a vast amount of evidence and advice from a range of different sources on the topic of End of Life Care in Northumberland.

They have sought to investigate all services provided starting with traditional health and social care services alongside housing; keeping people integrated within society, recognising the added problems of rurality; the role of religious and other groups; encouraging IT for older people in Northumberland and rolling out current practices such as the integration of loss and bereavement into school curriculums and work experience opportunities.

There is an identified need for communities to become more ‘compassionate’ and realise their joint responsibility for ensuring service provision is co-ordinated and aligned to provide an excellent end of life pathway of care, whilst reducing duplication and using resources more effectively.

They conclude that End of Life Care in Northumberland needs significant consideration and development, as a matter of urgency and the following recommendations are aimed at providing the answers to a number of questions:

RECOMMENDATIONS

RECOMMENDATION 1:

(i) That the "Good Death Charter" be recommended to the County Council for adoption and robust and workable outcomes be sought to implement the principles of the Charter for the benefit of those who live in the area.

(ii) That the "Statement of Commitment to Family and Friends with a Caring Role within End of Life Strategies" be adopted by the County Council to complement the "Good Death Charter", and workable outcomes prioritised by carers be used to implement the commitment principles for the benefit of carers.

(iii) That the Council appoint an officer and member as champions of End of Life Care in order to drive forward strategic leadership and ensure tangible outcomes.

RECOMMENDATION 2:

(i) That the emerging Northumberland Clinical Commissioning Group and Social Care strategic commissioners engage to identify a 'whole system' strategic vision which should be articulated in a new strategy for the development of End of Life Care Services (and their capacity) in Northumberland. Patients, and service users and other stakeholders, (for example Carers' Northumberland and social care providers) be involved in the development of the Strategy, which should include the following:

- **How patient choice will become a more important factor in the location of someone's end of life care and death**
- **How the system can better share care plans so that patients' wishes and status as an end of life care patient can be more widely known, particularly by paramedics and out of hours GPs**
- **How commissioners could support the rapid discharge programme from Hospitals**

- **Explicit articulation as to how community services for end of life care and hospice services will be improved and developed in both range and capacity to meet anticipated demand. The Group feels that community services for End of Life Care should be led by a community based physician, of consultant rank, and supported by specialist GPs.**

- **How an adequately resourced telephone advice line for those at the end of life and their carers could be provided and made sustainable through mainstream funding. Further, how that phone line could connect to community teams providing end of life care**

- **How services could become significantly more 24/7 in focus**

- **How residential and nursing homes will become an integral aspect of the delivery of high quality end of life care, whilst receiving adequate medical support**

(ii) This will be achieved by:

- **Measures by which the End of Life Care Strategy's implementation can be judged**

- **An explicit reference to the level of financial resource dedicated to the improvement of End of Life Care**

- **A commissioning plan as to how the above will be achieved.**

The Working Group would like to be involved with the development of that strategy.

RECOMMENDATION 3

(i) **The NHS and Social Care commissioners satisfy themselves that commissioned nursing and residential homes have sufficient capacity, support and skill, including support from the NHS services, to facilitate effective End of Life care on their premises. The Group would like to hear the outcome of this.**

(ii) **That NHS North of Tyne should work with Citizen's Advice and others to ensure that the key elements of the specialist benefits advice service for cancer, which they previously funded, continue to be available by other means.**

RECOMMENDATION 4:

That the County Council and Partners (commissioners and providers) recognise the identified need to ensure all End of Life Care services are co-ordinated and aligned to provide an excellent end of life pathway of care, whilst reducing duplication and using resources more efficiently.

RECOMMENDATION 5:

(i) Consideration be given to ways of disseminating information on the support and services available to all staff on a regular and inclusive basis, recognising that not all staff rely on IT.

(ii) Employees across the organisation that have an interest or influence in end of life services be identified and any training needs be established, with a view to empowering staff to become advocates for how their service can help as part of their day to day roles.

RECOMMENDATION 6:

Consideration be given to ways of disseminating information on the support and services provided by LegaCare with a view to generating funding.

RECOMMENDATION 7:

That the Corporate Director of Children's Services:

(i) Examine the potential for changes to the curriculum in schools to introduce the key concepts of the charter;

(ii) Provide opportunities for volunteering for those with a potential interest in a health and social care career, including end of life;

(iii) Identify the scope for extended services, adult education and learning for schools and families in relation to end of life care.

TERMS OF REFERENCE

The Working Group was established with the following remit:

- To establish the current spend on End of Life Care in Northumberland and ascertain where those resources are spent.

- To establish the range, nature and location of services available for End of Life Care in Northumberland, the capacity of those services and the level of need placed against them.

- To consider the implications of implementing 'A Good Death', in the light of current service provision in End of Life Care and the developments required to address future need.

- To consider what can be done by the wider community, other than the local NHS, to make a 'good death' the norm in Northumberland.

- To consider what could be done to ensure carers received adequate support, when caring for someone at the End of Life Care.

- To seek the views of the local health and social care economy on the current position of End of Life Care in Northumberland and the areas of development felt necessary.

To recommend to the Executive specific ways that the County Council can contribute to improving End of Life Care within Northumberland.

We feel we have met the remit.

ACKNOWLEDGEMENTS

I would like to acknowledge the advice, support and invaluable input from a wide range of individuals and organisations:

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INTRODUCTION AND BACKGROUND

In September the School of Health and Social Care at Teesside hosted a major annual conference on end of life issues. The intention of the *Building the Compassionate Community?* event focussed on the practicalities of implementing a broad public health approach to death, dying and bereavement. Discussions included Professor Edwin Pugh's reflections on the impact of the *A Good Death* charter, a comprehensive review of research into compassionate human resources policies and a description of practical ways used to build a compassionate community approach in Sandwell.

Workshop sessions focussed on the importance of engaging local authorities in the 'public health at end of life' agenda, making social housing more compassionate for the elderly and those approaching the end of life, the role of faith groups in building a compassionate community, and engaging schools and children in breaking the taboo.

Following this, and to inform the work of the Group, Professor Pugh gave a presentation to Council Members and interested parties about End of Life Care and the work currently being undertaken in the area.

> *"We have developed practical initiatives to implement the charter including: community engagement and support; a focus on equity and diversity; engaging faith and belief groups; supporting people in their choice of where they wish to die; compassionate human resource policies; and legal support for vulnerable people"* Good Death Advisory Group 2012

Professor Pugh advised that the three great causes of death in 1900 were infectious disease, childbirth and accident. These sorts of deaths are relatively quick and do not include a great period of disability, nor require a great deal of support, before death occurs. End of Life Care, therefore, was not a major concern.

The changing nature of health and healthcare problems, however, now dictates that other causes of death have now become the most prevalent. Such diseases as cancer, dementia and COPD are now significant causes of death, yet are increasingly 'treatable'. Nonetheless, the advances of medicine dictate that even those who eventually lose the fight against such illnesses will have had treatment for their conditions and as such, will live longer with the illness before dying.

The fact that people are living with illnesses for longer before dying, raises the very obvious questions of how does, and how should, society support such people at the end of their lives.

METHODOLOGY

Members agreed that this topic was extremely wide ranging with a number of challenges and issues from a Northumberland perspective. Reference was made to the presentation by Professor Pugh and Keith Aungiers held on 8 September 2011and the Palliative Care Conference on 9 September 2011 which some members and officers had attended.

Both of these events provided the Group with an overview of the main challenges and introduced them to the numerous individuals and organisations with an interest in ensuring "a good death" for those nearing the end of their life. Many of these people had kindly agreed to take part in the Review. It was recognised that there were lots of services available but a lack of current information readily available for patients at the palliative care stage and before.

Further, the University of Teeside published policy guidance following a study into End of Life services which helped inform the work of the Group.

It was suggested that officers prepare a work plan to include the key streams of work. These would include:

- Consideration and adoption of the "Good Death Charter" for Northumberland and how it can be implemented
- Consideration and adoption of the "Carers Charter" to supplement the above
- Compassionate Communities
- Legal issues and HR policies
- Social Housing
- Schools and Children
- Identified gaps in pathways and support
- Consideration of best practice.

Visits were arranged to North Tyneside Hospital Palliative Care Unit, St. Oswald's Hospice and the newly opened Palliative Care Unit at Wansbeck Hospital. Members spoke with two of the patients and found this extremely inspiring.

Also, all Members and employees were invited to an "Information Event, where information stands were provided by a number of service providers giving information and advice. Around forty people access the information, including members, employees and Sir Alan Beith MP.

Relevant speakers attended each session and informed a list of recommendations for consideration by the Executive.

The Working Group has sought to consider how the Council can influence implementation of the "Good Death Charter" by considering some key questions:

- How can individual choice be made a more important factor in the location of someone's end of life care and death?

- How can the health and social care system better share care plans so that individuals' wishes can be more widely known and respected?
- How can community and other services for end of life care be improved and developed to match the charter principles?
- How can services become more 'seamless' and available 24/7 in all locations?
- How can community interest and involvement in end of life issues be developed?

Finally, an information session for Councillors and key groups in Northumberland regarding End of Life Care was held in County Hall in February, 2012.

We hope our report answers some of those questions.

This event provided the opportunity for a panel of senior public health care academics, social care health practitioners and representative from the Churches Regional Commission to provide an overview of the issues and concerns relating to End of Life Care in Northumberland. The panel speakers acknowledged the importance of the work being undertaken in Northumberland relating to End of life Care and that the County's willingness to address such concerns, particularly at this time of limited resources from the Coalition government, was commendable. The hope was expressed that the information and suggestions gathered from the panel inputs and subsequent discussion would indicate possible new thinking and political commitment to take the end of life care developments further forward.

Three particular concerns were highlighted by the panel of experts and evidence from open discussion relating to end of life care:

- How to maximise 'community assets'
- The coordination of service and multidisciplinary practice is essential
- The impact of current policy and practice needed to be assessed in order to inform policy development and resource requirements

Again, we hope our work will help address those concerns.

FINDINGS

1. Where do we care for people at the end of their life?

Aside from *how* we care for people at the end of their life, there is also a debate to be had about *where* we care for them. Members heard that whilst 60% of people expressed a preference to die at home, only around 21% actually did so with 61% dying in hospital. Around 40% of deaths are those that could not be predicted and it is inevitable that a high proportion of those will take place in hospital.

Also, choices can only be respected and honoured if the capacity of services allows for the exercising of that choice.

Research indicates that a significant number of people would choose not to die in hospital, although whether services have the capacity to meet those demands is another issue. It would appear that there is presently a huge disparity between preferences and reality.

Appendix 1 shows the Number of deaths by district and the place of death in Northumberland 2007 – 2009.

> *"In England and Wales the trend up until 2003 has been for decreasing numbers and proportions of deaths at home, especially among older people. A reversal of this trend will be an enormous task."* Gomes and Higginson

According to research:

- 1 in 5 people over 65 will die in a care home.
- About 50% of deaths will occur within two years of admission *(Hockley et al 2004).*
- 27% of those residents are confused, incontinent and immobile. *(Bowman et al 2004);*
- more training in palliative care and knowledge is needed for care home staff. *(Gibbs 1995; Hall et al 2002).*

One quarter of care home residents will die in hospital, although 59% could have remained in a care home with extra support.

2. Breaking the Taboo.

Members discussed taking a public health approach to dying and how the "taboo" could be broken in order for people to have "a good death". To regard death and dying as a normal part of life and to realise that it is more than a

medical responsibility but the responsibility of a "compassionate community" – the wider community and non NHS organisations.

> *"The North East will have the highest quality services to support individuals (along with their families and carers) in their choices as they approach death. By a good death, we mean one which is free of pain, with family and friends nearby, with dignity and in the place of one's choosing"* – The Vision for the North East – NHS North East.

3. The Good Death Charter

Members were introduced to the *Better Health, Fairer Health* 'pledge':

> "*We will create a charter for end of life care, with a statement of the rights and entitlements that should be honoured both for the individual preparing for death, and for their carers and families. This should relate not only to medical and nursing care but to the behaviours of all agencies and sectors who deal with these issues"*

The North East is the first region in the UK to adopt a broad-based public health approach to end of life issues. A charter for *A Good Death* has been developed by a multi- agency advisory group following research into social attitudes and behaviours and joint working with the national *Dying Matters* coalition. Extensive public consultation, awareness and social marketing were carried out and 2,500 responses were received.

The Charter sets out the key principles for individuals and organisations in relation to good practice when dealing with people who are dying, their carers and families and the bereaved.

The overwhelming response was that the charter could help break the taboo and encourage people to talk more openly about death, whilst giving people information on what they could expect for their end of life care.

The Group were of the firm opinion that everyone should be encouraged to read and adopt the principles of the charter in order that individuals, organisations and the wider society can come together to create more compassionate communities within the north east to everyone's benefit. (Copy of the principles of the Charter attached as **Appendix 2**).

Members were also introduced to the "Statement of Commitment to Family and Friends with a Caring Role within End of Life Strategies". This statement, relating specifically to unpaid carers was developed as part of the "Delivering Choice Programme" led by Marie Curie across the region. The group considered the five commitment principles that carers involved in the programme felt were essential in supporting someone at the end of life.

It was agreed that the statement would support the Council in their development of audit tools to support qualitative feedback to demonstrate on-going impact and identify areas of concern.

RECOMMENDATION 1:

(i) That the "Good Death Charter" be recommended to the County Council for adoption and robust and workable outcomes be sought to implement the principles of the Charter for the benefit of those who live in the area.

(ii) That the "Statement of Commitment to Family and Friends with a Caring Role within End of Life Strategies" be adopted by the County Council to complement the "Good Death Charter", and workable outcomes prioritised by carers be used to implement the commitment principles for the benefit of carers.

(iii) That the Council appoint an officer and member as champions of End of Life Care in order to drive forward strategic leadership and ensure tangible outcomes.

4. The Role of the County Council

Local Authorities are uniquely placed to play a major role in the practical implementation of the *A Good Death* charter.

The Working Group considered a number of practical ways in which the "Good Death Charter" could be adopted and implemented across Northumberland across five cross cutting key Council roles and how the Council could influence these key areas across a spectrum of services and help change how society deals with dying and death:

- As a strategic leader
- As a provider of a broad range of services with an impact on End of Life
- As a major employer
- As a representative and shaper of local community views and interests
- As the local education authority

Aim as a strategic Leader to:

- *Drive strategic ownership, leadership and promotion my Leaders, Executive members, Health and Wellbeing Board and scrutiny;*
- *Formally adopt the Charter as council policy;*
- *Work with partners to develop a coordinated approach to end of life;*
- *Influence the Health and Wellbeing Board to embed end of life as a key priority*

It was considered very relevant that public health would soon be the responsibility of the Council and members recognised their dual role as both strategic leaders in the transition of public health but also as community leaders to assess, understand and influence local community views and needs through committees and councillors' surgeries.

The Council has established a Health and Wellbeing Board in shadow form which is chaired by the Leader of the Council. The Board has an underpinning structure of Groups including an Adult Commissioning Group and a Children's Commissioning Group. The Working Group feel that **the Health and Wellbeing Board, through the Commissioning Groups is the most appropriate platform to take forward their recommendations and ensure that End of Life services are among the public health priorities of all partners and grounded within the Joint Strategic Needs Assessment.**

RECOMMENDATION 2:

(i) That the emerging Northumberland Clinical Commissioning Group and Social Care strategic commissioners engage to identify a 'whole system' strategic vision which should be articulated in new strategy for the development of End of Life Care Services, (and their capacity), in Northumberland. Patients, and service users and other stakeholders, (for example Carers' Northumberland and social care providers) be involved in the development of the Strategy which should include the following:

- **How patient choice will become a more important factor in the location of someone's end of life care and death**
- **How the system can better share care plans so patients' wishes and status as an end of life care patient can be more widely known, particularly by paramedics and out of hours GPs**
- **How commissioners could support the rapid discharge programme from Hospitals**

- **Explicit articulation as to how community services for end of life care and hospice services will be improved and developed in both range and capacity to meet anticipated demand. The Group feels that community services for End of Life Care should be led by a community based physician, of consultant rank, and supported by specialist GPs.**

- **How an adequately resourced telephone advice line for those at the end of life and their carers could be provided and made sustainable through mainstream funding. Further, how that phone line could connect to community teams providing end of life care**

- **How services could become significantly more 24/7 in focus**

- **How residential and nursing homes will become an integral aspect of the delivery of high quality end of life care, whilst receiving adequate medical support**

The timescales this will be achieved by:

- **Measures by which the End of Life Care Strategy's implementation can be judged**

- **An explicit reference to the level of financial resource dedicated to the improvement of End of Life Care**

- **A commissioning plan as to how the above will be achieved.**

The Working Group would like to be involved with the development of that strategy.

Aim as a service provider to:

- *Review and where appropriate to re-design services related to death registration, funerals, cremation and bereavement*
- *Identify and re-design other relevant services across the range of council responsibilities to enable and support choice of where to die e.g. social care*
- *Work with housing providers to identify ways of supporting people to continue to live and die at home*
- *Work with partner organisations to develop seamless transition between services and 24/7 support in all areas of the County*
- *Identify the end of life needs of vulnerable and marginalised groups and seek ways of addressing them.*

Examples of the range and location of services available for end of life care in Northumberland

Northumberland Community Services:

Northumberland Community Services includes Macmillan specialist nurses and physiotherapists, Marie Curie nurses, Macmillan Bereavement Service, District Nursing and the Short Term Support service (including Macmillan Carers and Palliative Care at home.)

The Macmillan specialist nurses and physiotherapists work closely with GPs and District Nurses to provide palliative care, advice and support to patients, families and carers following diagnosis. They provide expert pain and symptom management and provide education and training to health professionals.

Three Marie Curie Nurses, based at Alnwick, Bedlington and Ashington, provide practical nursing interventions and therapies to allow people to remain at home and form relationships with patients, families and carers to provide emotional and psychological support, working closely with Primary Care teams and other specialists.

The Macmillan Bereavement Service is a volunteer based service which helps support adults following bereavement. A co-ordinator manages and supports the volunteers and provides training for them and the Primary Care Team.

District Nurses provide out of hours nursing and long term condition management and palliative care. The Short Term Support Service includes Macmillan Carers and palliative care at home for people with a palliative diagnosis. 100% positive patient feedback had been received.

Commissioners, NHS North of Tyne:

The Department of Health End of Life Care Strategy outlines a 6 step pathway:

- Discussion as end of life approaches
- Assessment, care planning and review
- Co-ordination of individual patient care
- Delivery of high quality services in various settings
- Care in last days of life, and
- Care after death

The aims of the commissioning group are to improve the standards of palliative care across Northumberland, enable more people to die in their preferred place and reduce the numbers of unnecessary admissions to hospital.

Palliative Care Funding – West Northumberland

A pilot pathway in West Northumberland included:-

- Advanced Palliative Care Register
- Advanced care planning and use of the Liverpool Care Pathway
- Home support increasing Tynedale Hospice at Home capacity
- 3 Community palliative care beds.

Discussions are ongoing between Northumbria Healthcare NHS Foundation Trust, the Clinical Commissioning Group and service providers in the West to agree forward looking arrangements as soon as possible. The Scrutiny Committee asked that they be informed of these arrangements.

Health Commissioned Community Services in Northumberland include the services mentioned above by Northumbria Healthcare NHS Trust, Hospice Care North Northumberland, Tynedale Hospice at Home, Learning Difficulties specialist Macmillan Nurse and a Community Palliative Care Consultant.

In-patient care is provided at Wansbeck General Hospital and the Community Hospitals, Marie Curie Hospice and St Oswald's Hospice (for adults and children).

Service provision is of a high quality; however, connectivity between services is not always clear. Further work is needed on the whole pathway. The above pilot proved excellent in gaining information to inform this work.

Commissioners of Social Care:

The document *Supporting people to live and die well: a framework for social care at the end of life* was published in July 2010 by the national end of life care programme and launched regionally in March 2011and Keith Aungiers and Professor Pugh took part in the launch conference. This aims to plan for the improvement of end of life care in different social care settings and at different geographic levels.

A significant outcome from the discussions is the proposal for research into dementia and end of life. In October, the *Later Life* and *A Good Death* advisory group agreed to develop a collaborative research project proposal on dementia and end of life care, with the potential for this to be funded from the national Social Care Framework programme.

Its overall aim would be to enable the wishes and needs of those who suffer from dementia to be articulated, recognised and acted upon. This would aim to ensure that in the (sometimes long) degenerative period before death they would receive the best and most appropriate support and care, and be treated at all times with respect, dignity and compassion.

The main objectives would be to:

- build on existing research into what makes a 'good death' to develop a unique evidence base of what matters most to people with dementia as they approach end of life
- build up practice-based evidence of what works and what does not
- identify the characteristics and skill requirements of those who care for people with dementia in a range of settings
- **evaluate and disseminate the findings from the project for adoption elsewhere.**

Within older people's residential and nursing care, quality standards were introduced in 2008 and fee levels are linked to assessments against these standards.

Within Northumberland, there is a robust process in place to ensure residents and families are consulted about their end of life wishes.

Other services provided include home care and adult and specialist services and joint work with health commissioners and other providers to provide training and support. The aims of the service are to ensure that wishes are recorded and embedded within support and that flexible funding will allow choice to be supported. Also that services are linked together to work more effectively.

Members were given an explanation of the 'Liverpool Model' - a co-ordinated and integrated pathway delivered by Liverpool End of Life Care specialists region wide.

Referring to figures provided by Professor Pugh, a significant number of people are dying in hospital or care homes which are not their preferred place of choice**.**

It was suggested that commissioners needed to review their services in order to address this.

RECOMMENDATION 3

(1) The NHS and Social Care commissioners satisfy themselves that commissioned nursing and residential homes have sufficient capacity, support and skill, including support from the NHS services, to facilitate effective End of Life care on their premises. The Group would like to hear the outcome of this.

(II) That NHS North of Tyne should work with Citizen's Advice and others to ensure that the key elements of the specialist benefits advice service for cancer, which they previously funded, continue to be available by other means.

Marie Curie:

The Marie Curie Newcastle Hospice includes a 22 bedded unit providing specialist palliative care. The hospice receives referrals for end of life care, respite, symptom control and emergency/crisis from acute trusts, community teams, the day hospices and other health or social care professionals.

Referrals were for cancer but also neurological conditions such as Parkinson's or MS and also organ failure. In 2011, 399 patients were admitted, 3813 occupied bed days (92% cancer), with an average length of stay of 12 days.
The in-patient unit provides 3 bays of 11 beds, all with direct access to the garden. All side rooms are en-suite and have facilities for relatives to stay. A family suite is currently being developed. End of life care, emotional, physical and bereavement support services are offered, by social workers and trained volunteers.

The Day Hospice caters for referrals for symptom control, social isolation, respite, psychological support and complementary therapies. A multi-disciplinary team including doctors, nurses, physiotherapists and occupational therapists provided treatments and support to 1,375 attendances in 2011.

Nurse Practitioners enable highly qualified nurses to work within the medical team. The aim is to recruit and train 8 to provide 24/7 cover, offering pre-admission visits, in-patient admissions, reviews, discharge follow up and outpatient assessments. A 'Reflection Room' built in 2010 provides a calming room to give carers, patients and staff space to relax.

Parkinsons UK

Parkinsons UK is a support and research charity seeking to find a cure and improve life for those affected by the condition. The Group heard that 1 in 500 of the general population (1 in 50 of those aged over 80) suffer from Parkinson's with a 28% increase expected by 2020.

A new guide has been developed by the National Council for Palliative Care following a survey of experts which expressed concerns about diagnosing dying, excluding reversible clauses, withdrawing medication and symptom control. The charity has produced a booklet giving practical advice on the later stages of the condition (www.parkinsons.org.uk), and a professionals' network provided free for all health and social care professionals.

End of life Clinical Innovation Team

Lynda Deardon, North East Strategic Health Authority, updated members about the work carried out by the End of Life Clinical Innovation Team culminating in the "Deciding Right" initiative, the first UK regional initiative that integrates three national legal and clinical frameworks:

2005 Mental Capacity Act
2007 BMA/RC/RCN joint statement on cardiopulmonary resuscitation decisions
2011 NHS end of life guidance on advance care planning.

"Deciding Right" unifies existing frameworks to empower individuals to make decisions that can have legal authority and empowers professionals to recognise those decisions in partnership with patients of all ages and all abilities.

RECOMMENDATION 4:

That the County Council and Partners, (commissioners and providers), recognise the identified need to ensure all End of Life Care services are co-ordinated and aligned to provide an excellent end of life pathway of care, whilst reducing duplication and using resources more efficiently.

Aim as an employer:

- *revise human resources policies to include compassionate features for employees in caring roles, with terminal illness or following bereavement*
- *use the staff newsletter/web site to identify the council as a compassionate community*
- *review the full range of council policies (e.g. housing) to ensure that they are consistent with and promote the principles of the Charter*
- *using a broad definition, identify all staff whose actions might have an effect on the end of life experience of individuals and their carers*
- *ensure that training becomes a requirement and is made available to all staff with end of life responsibilities (through e-learning).*

Human Resource Policies

NCC do not have specific HR policies relating to End of Life Care but feel it more appropriate to avoid being too prescriptive and allow Managers and Heads of Service to consider individual cases of anyone facing or caring for someone with a life threatening condition.

Following the recent implementation of Single Status, all HR Policies are being revised over the next 12 months. **It was suggested that any recommendations arising from the work of this Group could be considered for inclusion**.

Whilst the average age of NCC employees is 43, it was recognised that life threatening conditions were not limited to any age.

The Group were reassured that NCC had a number of relevant policies in place:

- the Flexi Scheme is regarded to be extremely generous allowing employees to take off an extra 26 days per year, virtually doubling

their annual leave allowance. This allows the freedom to cover arrangements themselves.

- Adjustments are made for employees with ongoing conditions to attend medical appointments.
- The sick leave adjustments are again very generous – allowing full pay for six months and half pay for a further six months though whether this would continue was debatable given the current market.
- Leave of absence was the main tool used in such cases.
- The Compassionate Leave policy allows 5 days per year time off to care for unforeseen circumstances regarding dependants, for example admission to hospital.
- The Bereavement Leave Policy allows up to 5 days at the discretion of the Head of Service.
- Keep in Touch and Career Break Schemes were also available. This allows a fast route back to work by guaranteeing an interview if the employee wishes to return to work, subject to a suitable vacancy being available.
- The Alternative Employment Scheme allows some flexibility. If an employee is struggling to cope with their job, they may be redeployed to another role to allow more home/work balance.
- There can be some variations made to contracts of employment such as the “step down” or “step aside” whereby the employee allows others to take over their role temporarily until they feel more able to cope and they are given alternative duties for that period.
- Employees may be allowed to work reduced hours.
- NCC has a home working policy where employees are able to work full or part time from home. The IT infrastructure is being updated to allow this option to be made available to more employees.

Managers are usually very supportive in seeking the best option for any employee facing personal problems, negating the need for very prescriptive policies.

However, many employees were unaware of the support available to them.

The Welfare Service

The Welfare Officer provides counselling and advice for those requesting help and also advice and information regarding benefits. It was recognised that many people wish to deal with personal matters themselves without involving work colleagues.

The Pension Service can provide advice on options available to employees including retirement, redundancy or other types of release and the pension implications.

Support is available for all employees not just those based in County Hall, through self-referral, manager's referral, or managers seeking advice confidentially on behalf of an employee.

Cases were described to the Group which illustrated the role of the Welfare Service and the different support given to the employees concerned and their families.

Members raised the question of capacity of the Welfare Officer given the number of NCC employees. It was also recognised that there could be incredible stress placed on the Welfare Officer given the emotive and difficult cases dealt with but were reassured that the number of referrals was manageable. The officer is registered with the British Association Counselling Psychotherapy, which states she has to have 1.5 hours monthly external supervision to monitor her own welfare.

However, among welfare referrals, the number of End of Life Care cases is quite low and the Occupational Health Unit provided extra support. Also, employees had usually been referred to many other services by their GP prior to contacting the Welfare Service and were already receiving support.

There is also a very important role to play in providing after care support to employees returning to work.

It was recognised that many wished for their personal circumstances to remain private but it was suggested that many members of staff were unaware of the policies and the services available. **There was a need for more communication and promotion of the support available, recognising that the majority of staff did not use computers in their roles.**

RECOMMENDATION 5:

Consideration be given to ways of disseminating information on the support and services available to all staff on a regular and inclusive basis, recognising that not all staff rely on IT; and

Employees across the organisation that have an interest or influence in end of life services be identified and any training needs be established, with a view to empowering staff to become advocates for how their service can help as part of their day to day roles.

LegaCare

LegaCare is a Legal charity based in Northumberland which provides legal advice and support to people with life threatening illness, and their families. It has the

support of Professor Edwin Pugh and also Professor Sir Mike Richards, CBE, National Director of Cancer Services.

Clients will usually be referred by a medical practitioner and the service is free to those earning less than £30,000 per year. Clients earning over that amount could receive the service for a contribution to the charity. The service has to be controlled given the capacity of the two solicitors currently providing the advice. LegaCare offices are welcoming, friendly and accessible and unlike the stereotypical solicitors office which can be inhibitive and uncomfortable to some people, especially those facing such emotive circumstances.

The areas of law covered include:

- Employment
- Debt and Mortgage advice
- Guardianship and matrimonial
- Insurance Disputes
- Personal Injury and
- Probate.

Out of the 100 or so Clients helped, over 75% are at the palliative care stage and under the age of 60. Many of them have very complex legal issues that need resolving.

The service has been piloted in the area from Berwick Upon Tweed to North Yorkshire, in collaboration with Northumbria Healthcare NHS Trust, 13 hospices, and 49 GP surgeries in Northumberland. Macmillan and Northumbria Adult Services have provided funding for two years. They also currently have 12 law students providing invaluable support (as well as gaining excellent work experience). This will allow approximately 4,800 cases to be assisted over the funding period.

Presentations have been given to Doctors, Nurses, Occupational Therapists, Social Workers, Case Managers and Community Matrons to help them identify where legal help may be needed and how to access that help. On behalf of their Clients. The information is being cascaded to other relevant staff.

The group commented that the availability to access this service could provide vital peace of mind and quality of life for people already facing traumatic circumstances but recognised that sustainability of the service was dependent on sufficient funds.

There was a need to promote the service with a view to generating funding.

RECOMMENDATION 6:

Consideration be given to ways of disseminating information on the support and services provided by LegaCare with a view to generating funding.

Aims of a Community Leadership role:

- Council Members, in their community leadership role, to assess, understand and influence local community views and needs through surgeries and area committees
- Act as personal advocates for the principles of the Charter
- Identify and promote opportunities for adult volunteering
- Disseminate information and advice to promote societal change in attitudes and behaviours e.g. through Northumberland News

Compassionate communities

The *Compassionate communities* unit at Teesside University has carried out nationally recognised, innovative work to promote the charter and stimulate the compassionate communities approach. They have examined ways in which existing palliative care modules at the university could take on a more public health approach to end of life. A public health foundation module workshop commenced during the year, opening up opportunities to reach 500-600 students annually. The project also delivered workshops in a primary school setting and a programme of work with sixth forms in local schools.

A pilot study examining the human resource (HR) environment around end of life was carried out with additional funding from the university. Its objectives were to: explore the statutory position relating to carers and the bereaved; examine the views of trade unions and professional organisations; review current HR policies of large employers; investigate the degree of flexibility of policies; and listen to employees' experience. A comprehensive report of the main findings from the study is now available and will act as a guide to organisations wishing to adopt a more compassionate approach towards employees who have caring responsibilities for someone at the end of life or are bereaved.

The project ended in October and Professor Shucksmith and Sarah Russell attended the meeting in March to report of the successes, areas of difficulty, lessons learned and prospects for further development.

All members of the council and Corporate Directors were invited to the discussion given the cross cutting responsibilities.

Voluntary and community sector engagement

The Working Group agree that engaging with voluntary and community sector organisations is vital to informing the wider public about services and support available.

At a recent conference the message was:

- support and services in some areas were very good but coverage was patchy across the north east
- diagnosis with a terminal illness should not lead to 'labelling' of the person or demean the value of their life and worth to the community
- VCS organisations could provide a single focus of support and a conduit between GPs and the community, where engagement was difficult
- current prospects for funding were placing increasing demands on the VCS which might need new ways of working
- it is important to ensure that the charter is accessible to all parts of society, including through alternative language and easy read versions
- education and popular media are ways to break down barriers and engage young people.

The stalls manned by different organisations at the information event referred to earlier were effective in explaining what services various organisations provide in an informal way.

Mr. McIndoe from Northumberland Local Involvement Network (LINks) is a member of the Working Group and provides a link between the two. This will promote the aims and objectives of the charter to the residents of Northumberland.

Death, dying and faith perspectives

> *Being aware of and tackling questions of faith, belief and spirituality is vital if the principles of the charter are to be accepted so that death and dying become normalised.* Good Death Advisory Group, 2012

Paul Southgate, Chief Executive of the Churches Regional Commission, reported on a major conference *What is a Good Death? - Understanding Death and Dying from Different Faith Perspectives* which sought to engage productively with faith and inter-faith organisations from different religions and denominations in different parts of the north east and also communication with humanist and non-faith organisations.

Housing

Edwin Pugh and Keith Aungiers shared with the Group a pilot initiative with Home Housing Group to support people to live at home. The project has been designed to support people who are coming to the end of their lives or have been diagnosed with a terminal illness, helping them to make practical arrangements and choices which would enable them to remain in their own homes with the best quality of life for as long as possible.

Following a successful bid earlier in the year, the *Support and Time to Think* project received funding from the North East Health Innovation Cluster, with additional funding coming from Newcastle Science City. The pilot is also supported by Marie Curie and Age UK. The first clients were supported from September 2011.

> *"Many people may be housebound or restricted from accessing their local support and community networks. Staff and volunteers play a vital role in supporting people and their families across a range of areas such as: organising aids and adaptations; applying for benefits; putting personal affairs in order; learning a new skill; taking up a new hobby; using IT to contact distant relatives; and having someone to talk to."* **Good Death Advisory Group 2012**

So far a dozen social housing clients have joined the pilot, each with a different terminal diagnosis, of differing ages and from a variety of family and support circumstances. It is currently administered by a single support worker, but the aim is to extend it to 40 clients by the end of the nine-month trial.

The County Council's housing policies include:

- adapting properties through Disabled Facilities Grants (£1.7m this year)
- provision of Chronically Sick and Disabled Payments
- Care and Repair Northumberland
- Personalised packages of home support
- Community care assessments and
- Specialised services through Macmillan, Dementia Care Partnership, Age UK etc.
- OT assessments
- Telecare and Telehealth
- Advice and support and practical health in ending a tenancy to protect the rights of the tenant and succession rights.

"Awareness of the charter and its principles is fundamental to stimulating changes in people's attitudes and behaviour. To be successful we need the support of all organisations and agencies, as well as members of the public." Edwin Pugh.

Aim as an education authority:

Children cannot be protected from death. Members heard that from the age of eight, many children understand that death is permanent and happens to everyone. However, it is still as difficult for them as it is for adults. There is a need to talk to children about dying to dispel myths and help them have an understanding of death, funerals, burial and cremation before being confronted with those things when someone close to them dies. Dying matters (www.dyingmatters.org) address talking to children about death and suggest a number of ways of approaching it.

Schools can provide the opportunity for such discussions.

RECOMMENDATION 7

That the Corporate Director of Children's Services:

(i) Examine the potential for changes to the curriculum in schools to introduce the key concepts of the charter;

(ii) Provide opportunities for volunteering for those with a potential interest in a health and social care career, including end of life;

(iii) Identify the scope for extended services, adult education and learning for schools and families in relation to end of life care.

CONCLUSION

End of Life Care in Northumberland needs significant consideration and development, as a matter of urgency.

The Working Group submit their recommendations for endorsement and seek the cooperation of all of the organisations represented on the Working Group to provide an Action Plan of achievable outcomes that ensures a co-ordinated pathway of end of life care in Northumberland.

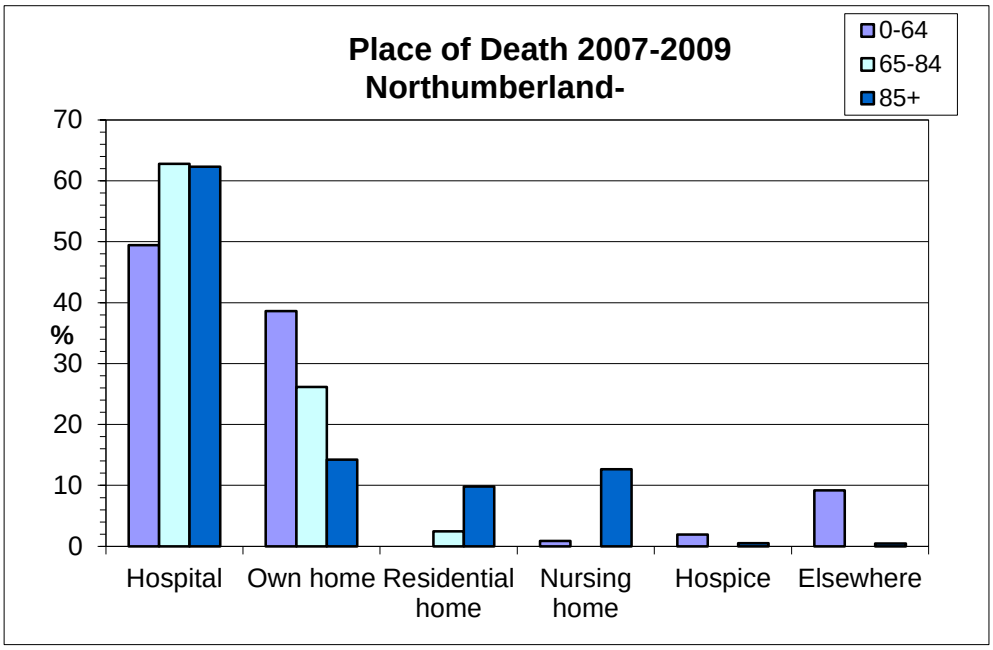
BACKGROUND PAPERS

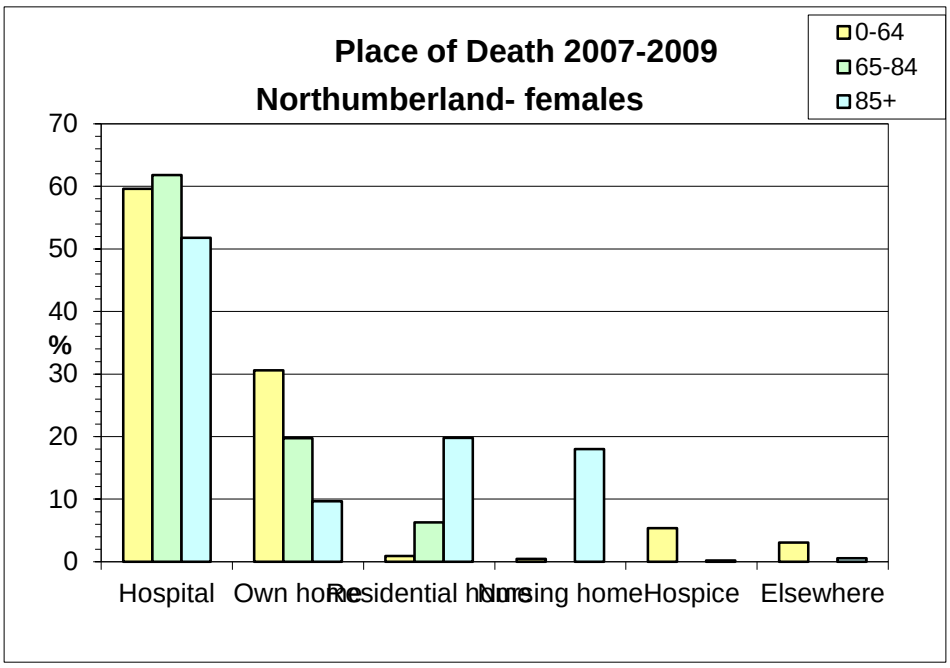
The following background papers and information can be made available on request:

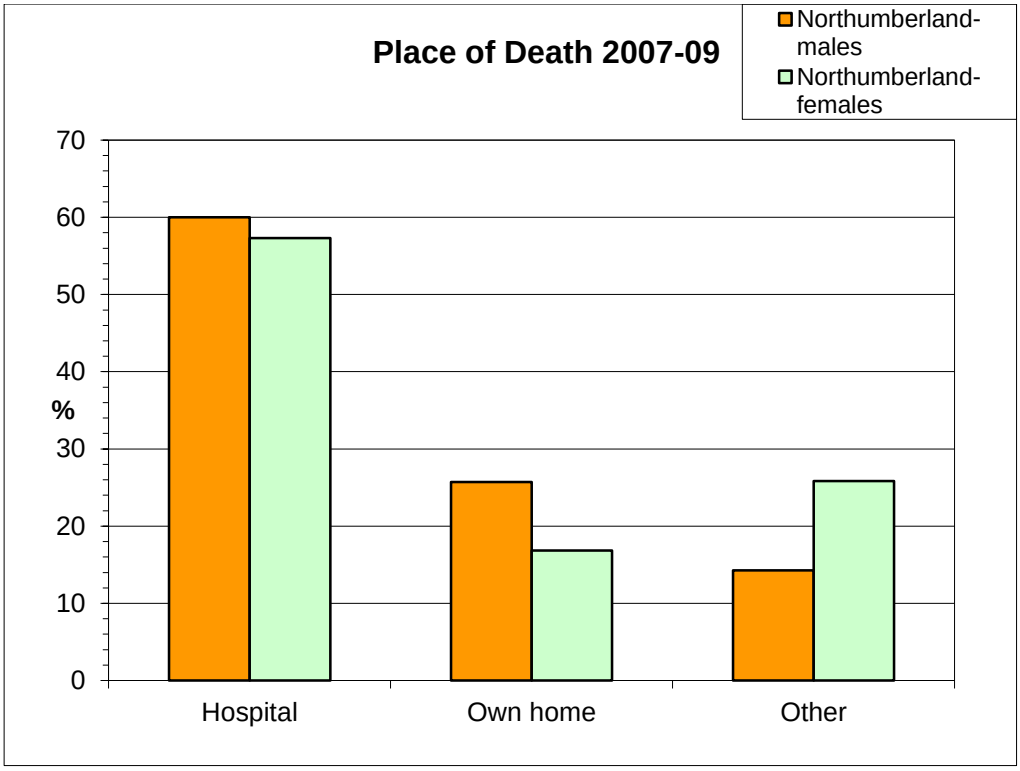
North East Charter for a Good Death
Number of deaths by district and the place of death in Northumberland 2007 – 2009.
Department of Health End of Life Care Strategy 2010
National End of Life Care Programme: Supporting people to live and die well.
Dying Matters Leaflet
Legacare Mission Statement
Dying Matters newsletter
Northumberland Carer's Charter
Talking to children about dying - leaflet
Why dying matters to all of us – leaflet
The Golden Guide
Glossary of Terms

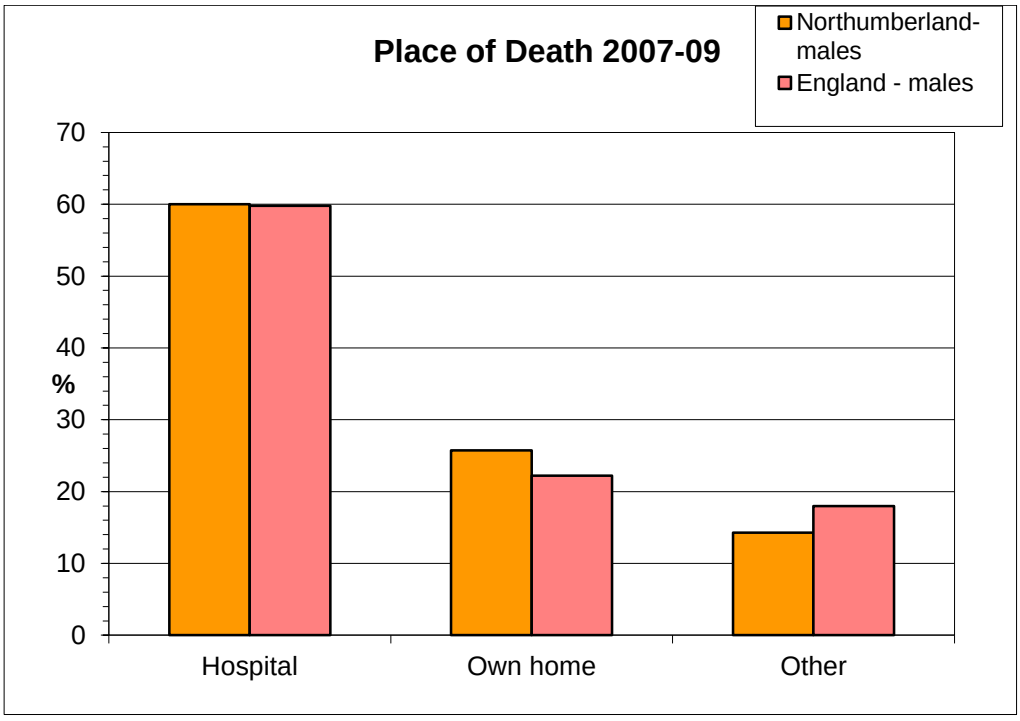
Powerpoint presentations:
Dying Matters
End of Life Care - Facts and Challenges
Compassionate Communities
Housing Services
The role of Faith Groups
Engaging schools and breaking the Taboo
Marie Curie
LegaCare
Parkinsons UK
End of Life Clinical Innovation Team
Northumberland Community Services
Commissioning North of Tyne
Social Care Commissioning
Compassionate Human Resources policies for patients and carers

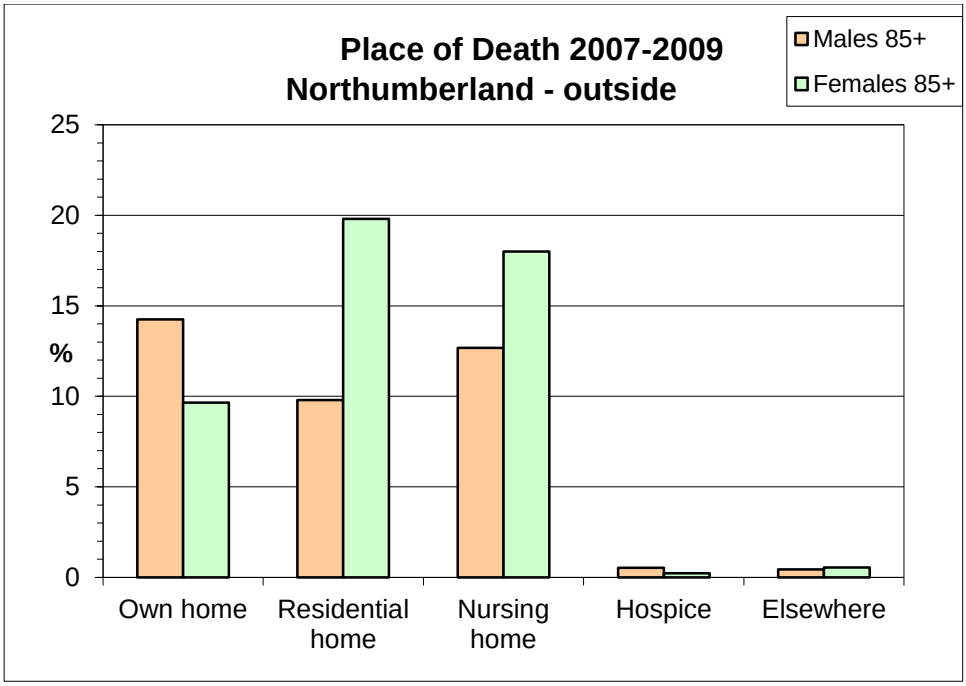
APPENDIX 1 – Place of Death

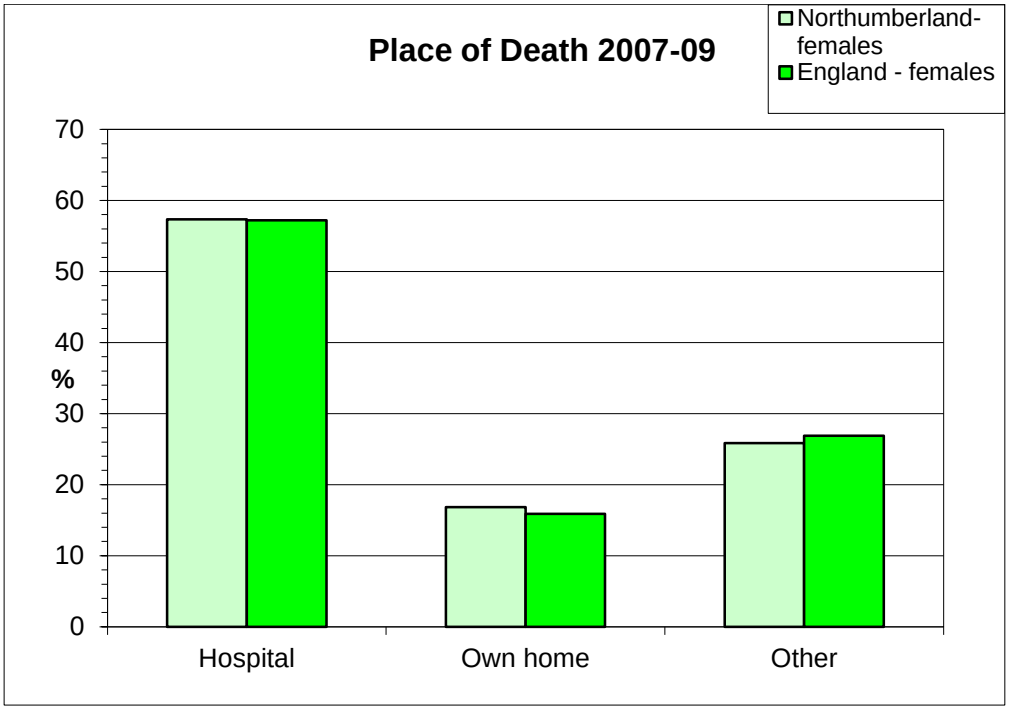





Place of Death 2007-09
Northumberland-males
Northumberland-females
70
60
50
40
%
30
20
10
0
Hospital
Own home
Other


Place of Death 2007-09
Northumberland-males
England - males
70
60
50
40
%
30
20
10
0
Hospital
Own home
Other


Place of Death 2007-2009
Northumberland - outside
Males 85+
Females 85+
25
20
15
%
10
5
0
Own home
Residential home
Nursing home
Hospice
Elsewhere


Place of Death 2007-09
Northumberland-females
England - females
70
60
50
40
%
30
20
10
0
Hospital
Own home
Other

APPENDIX 2

NORTH EAST CHARTER FOR A GOOD DEATH

COMPASSION AT 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 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 organisations, groups or individuals who plan, develop and provide end of life care or 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 a part of life.
- To be treated with dignity, respect and privacy, according to our wishes.
- To value each individual and the contribution we may still wish to make to our family, job or social network, in a caring and supportive way.
- To have clear, honest and tailored information and good communication throughout illness or frailty.

Time to plan:

- If appropriate, to be told clearly and compassionately the reality that death is coming.
- To be provided, where possible, with a sense of 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, social care and all other 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 organise and coordinate 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 affect 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 counselling if required, for families, partners, carers and staff. This may be before or after death occurs.

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

It has been updated and amended to take account of the views expressed by members of the public and professionals during the consultation exercise which ran between October and December 2009.

May 2010