Living and Dying Well in Lothian

Lothian's Palliative Care Strategy 2010 – 2015

Public Consultation

Summary guide to the strategy

Contact details

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Contents

Background 1
Our vision for palliative and end of life care 2
What we have already said we are going to do 3
What do we mean by palliative care? 3
What the strategy will aim to do and what's involved 4
The main objectives of our strategy 5
Identifying people who need palliative care 5
Improving our assessment and care planning 5
Supporting and improving care in care homes 6
Supporting and improving care in hospitals 6
Improving care for children and adolescents with palliative care needs 6
Redesigning palliative care pharmacy services 7
E-health development and improved use of data 7
Developing our education, training and workforce 8
How will we know the strategy is working? 9
What it will cost 9
More information and responding to the consultation 10
Consultation questions 11

Background

NHS Lothian and partner organisations are working together to improve services for people who require palliative and end of life care.

This strategy is an important step in making that improvement happen. It has been drawn up with input from a wide range of people, including health professionals and carers. The strategy outlines how we would like to take forward the development of palliative and end of life care services in Lothian over the period 2010 – 2015.

Each year in Lothian approximately 7,500 people die from a wide range of causes. In common with the rest of Scotland, the largest single underlying causes of death are heart disease, cancer and cerebrovascular disease, including stroke. Across Lothian, people die in a range of places too. More than half of deaths each year in Lothian (57 per cent) happen in a hospital setting; 21 per cent of people die at home; 14 per cent in a care home; and 8 per cent in a hospice.

Care for patients with life-limiting conditions, and for those who are dying, is therefore delivered by a wide range of health and social care professionals, across many settings in Lothian. For this reason our strategy aims to make it easier for people to access the help and services they need, earlier in their illness than they do currently. We also want to respond better to the wishes and needs of patients – and their families – over where they are cared for and where they die.

In the near future, between now and 2016, the number of deaths in Lothian each year will fall slightly. After this the number is expected to start to rise again and is expected to continue to grow slowly each year until we reach a level of approximately 8,200 deaths a year by 2030/31. One of the main reasons for this change is that more people will continue to live for longer in our population. As the population ages, alongside other population changes, we'll have a greater proportion of elderly people in Lothian. More of these people will live with long-term conditions, and many of them will have more than one long-term condition.

Therefore, to meet the increasing demand and complexity of care in the future, we have to take steps to improve palliative and end of life care now.

Our vision for palliative and end of life care

Our **vision** is for high quality palliative and end of life care available in all settings, used by all who require it, and prioritised according to the needs of patients, rather than their medical condition.

By 2015, clinical teams in all settings across Lothian will be reliably identifying and assessing patients as they reach a palliative phase of their illness, and developing and updating integrated care plans for them and their carers, based on patients and family preferences. More people will die in the place of their choice.

Our **aim** is to ensure access to high quality palliative care to all who need it, irrespective of diagnosis, age, gender, ethnicity, religious belief, disability, sexual orientation, and socioeconomic status.

We have identified through local research, audit and public involvement eight **key challenges**, to:

1. improve care for people living with **any life-limiting illness**
2. have in place clear processes in all care settings for identifying people who are in the palliative phase of their illness
3. provide palliative care and support throughout the palliative phase rather than just in the terminal stage
4. provide high quality integrated palliative care to more people in the **setting of their choice**, including support for preferred place of death
5. **better care for all aspects of the person**, physical, psychological, social, spiritual and to improve patient experience
6. have **effective systems to share information**, between the people involved in a patient's care
7. provide people with optimal care in the last few days of life
8. promote community involvement and a public discourse about death and dying.

What we have already said we are going to do

NHS Lothian has already developed an action plan (our Living and Dying Well Delivery Plan for 2009-11) and has submitted this to the Scottish Government. This commits us to delivering changes and improvements.

The Living and Dying Well Delivery Plan includes actions on improving the way that clinical teams work; better care planning, and communicating better across our services about people's conditions and their wishes and needs, to improve the way we co-ordinate care (for example between day time and out-of-hours clinical teams).

In 2009 the Lothian Palliative Care Managed Clinical Network finalised its review of specialist palliative care bed capacity in Lothian. This review made a number of recommendations, including the need to develop more community-based ways of delivering palliative care, while keeping and using the specialist beds that we have got in the best way possible.

More details of these plans can be found in the full version of the strategy and on the consultation website:
www.nhslothian.scot.nhs.uk/ladwinlothian

What do we mean by palliative care?

The World Health Organisation defines Palliative Care as: *'an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.'*

The World Health Organisation has also recommended that planning for care at the end of life should be responsive to patient choice regarding place of care and place of death.

The Standing Medical Advisory Committee and Standing Nursing and Midwifery Advisory Committee outlined the following definition of palliative care, which usefully emphasises the progressive component of illness, and the co-ordination of care:

'Palliative care is active total care offered to a patient with a progressive illness and their family when it is recognised that the illness is no longer curable, in order to concentrate on the quality of life and the alleviation of distressing symptoms within the framework of a co-ordinated service.

'Palliative care neither hastens nor postpones death; it provides a relief from pain and other distressing symptoms and integrates the psychological and spiritual aspects of care. In addition it offers a support system to help during the patient's illness and in bereavement. "Family" is used as a general term to cover closely-attached individuals, whatever their legal status.'

What the strategy will aim to do and what's involved

We want to deliver care which includes palliative care and support as early as possible for people who need it and who would benefit.

While previously people would be offered palliative care as they neared the end of life, and when it was no longer possible to actively treat their disease, our vision is for people to be offered a palliative care approach to their care at a much earlier stage.

This does not mean that appropriate treatment of disease or the management of symptoms will stop, but we believe that many people would benefit from starting to discuss earlier with their carers, including health and social care professionals, the life-limiting nature of their illness.

This will help because things such as where you'd like to be looked after, what kind of treatment you want (and don't want), and personal issues such as home, family and care arrangements, can be discussed and planned for and everyone involved in providing care will know where you would prefer to die and what help you will need.

We will aim to support this by breaking down palliative care planning and delivery into three tiers or levels:

- working with people with **Long Term Conditions** to make sure that the need for palliative care is identified as part of routine care at the earliest stage appropriate, helping people to plan, direct and be actively involved in their own care.
- adopting the **Palliative Care Approach** from as early a stage as is agreed appropriate. The palliative care approach seeks to maximise quality of life, by maintaining good symptom control, offering holistic assessment, including family and carers needs, and seeks to agree choices around treatment options, place of care and preferred place of death
- planning for and managing **end of life care** in the last days of life in a tightly co-ordinated and structured manner.

The main objectives of our strategy

Identifying people who need palliative care

We'll seek to do this by:

- supporting and encouraging our clinicians to ask themselves if they would be surprised if their patient were to die in the next 12 months, and if not, to start to introduce and discuss palliative care with their patient
- promoting and using the prognostic indicator guides that we have
- working with hospital clinicians to identify people who may benefit from a palliative approach on discharge and communicate this information to GP and primary care services
- supporting the Direct Enhanced Service for Palliative Care (DES – Palliative Care) in General Practice, to identify and register as many people as possible in the palliative phase of illness
- introducing the Liverpool Care Pathway for the dying patient (a recognised journey of care for people needing end of life care) in all settings to support identification and co-ordinated care for those in their last few days of life
- working closely with education providers to increase awareness of concepts of how people die (such as the 'Trajectories of Dying' concept – which is explained in our strategy document), the palliative phase and palliative care approach to care, rather than link palliative care to either prognosis or diagnosis exclusively.

Improving our assessment and care planning

We'll seek to do this by:

- promoting the recognition of the benefits to early identification of when someone's illness reaches the palliative care stage
- developing the systems we use for planning care – to better anticipate health and social care needs, and to support people making decisions about fundamental aspects of their care at an early stage
- using schemes such as the palliative care register in general practice, and the Direct Enhanced Service for Palliative Care, to encourage and support improved care planning and care co-ordination in the community
- developing electronic palliative care summaries for patients, when patients want these, which will explain and communicate details about their illness, medical care, patient wishes, and carer and support details, and allow us to share this information 24 hours a day across clinical teams.

Supporting and improving care in care homes

We'll seek to do this by:

- better partnership working between care home providers and health and social care staff. A Lothian Care Home Providers Palliative Care Reference Group is already in place and is chaired by our Lead Nurse for Cancer and Palliative Care
- building on what we have already done and know to be effective. Several schemes in Lothian have already demonstrated how we might improve the delivery of palliative and end of life care in care homes
- developing collaborative working and support from specialist palliative care services to help care home providers improve palliative care for their residents.

Supporting and improving care in hospitals

We'll seek to do this by:

- seeking to avoid re-admitting patients to hospital where good care planning in advance could have avoided this
- addressing the challenges to delivering high quality palliative and end of life care within Lothian hospitals for the significant number of people for whom admission is appropriate, and for those who choose to die in this setting
- integrating effective palliative care systems throughout hospitals to address these issues by, for example, using recognised tools to support and develop practice. We will also seek to improve communication between different parts of the health service – for example, between hospitals and a patient's GP.

Improving care for children and adolescents with palliative care needs

We'll seek to do this by:

- working in partnership with the Scottish Children and Young People's Palliative Care Network (SCYPPCN)
- developing a Do Not Attempt Resuscitation policy within the paediatric setting in 2009/10
- exploring the gaps in out-of-hours Community Children's Nursing Provision and developing proposals to improve future provision
- providing further educating and development for our staff to ensure health and social care professionals are equipped with the knowledge, skills, competence and confidence to care for children and young people and their families living with and dying from any advanced, progressive or incurable condition

- working on issues identified to us as important by our health and social care professionals in children and young people's services. These include:
  - > supporting choice of place of care and death
  - > effective co-ordination of care
  - > developing palliative and end of life care services that can respond to the specific needs of children and young people
  - > education and training
  - > supporting families.
- recognising that much of the overall framework for adult palliative care, and the development of systems and tools to support improvements in practise, are relevant and could be adapted for use with children and young people.

Redesigning palliative care pharmacy services

We'll seek to do this by:

- supporting anticipatory prescribing through information in the Lothian Palliative Care Guidelines and through implementation of the Liverpool Care Pathway
- reviewing the existing NHS Lothian Palliative Care Pharmacy Network to aim to ensure we provide access to medicines at all times
- supporting enhanced communication with primary care teams and community pharmacies via additional specialist pharmacists
- increasing opportunities for education and training on pharmaceutical issues to a range of health professionals.

E-health development and improved use of data

We'll seek to do this by:

- installing NHS secure data network connections to both Lothian independent hospices. This will support the secure exchange of clinical information and enable electronic referrals
- implementing an electronic Palliative Care Summary (ePCS) across Lothian. The ePCS will, with patient consent, enable transfer of information collected by GP practices to a central information store and make this available to Out of Hours (OOH) services, NHS 24 and Accident and Emergency (A&E) services
- scoping the potential to further integrate hospital specialist palliative care administrative data systems
- developing a more comprehensive approach to whole systems activity monitoring
- developing local health intelligence reports based on key indicators of performance against strategic goals.

Developing our education, training and workforce

We'll seek to do this by:

- working collaboratively with NHS Education for Scotland (NES)
- delivering a range of creative learning and development approaches to palliative care education at all levels, to ensure an appropriately skilled health and social care workforce
- ensuring information on education initiatives in specialist and generalist palliative care are made available in a range of formats, both electronic and paper-based
- exploring opportunities for resources to allow staff to access education
- integrating and dovetailing palliative care education with other relevant projects and initiatives, for example, Long Term Conditions, to address key themes identified within this strategy
- developing the volunteers and informal carers in all settings
- developing 'generalist' staff in all settings to provide better palliative and end of life care.

How will we know the strategy is working?

We will measure our performance on improving palliative care services in a number of ways. Page 37 of our strategy document outlines how we will do this.

We will look specifically at place of deaths indicators and we expect to:

- reduce the proportion of deaths in acute hospitals in Lothian (Royal Infirmary of Edinburgh, Western General Hospital, St John's Hospital, Royal Hospital for Sick Children) from a 2008 baseline of 42.3%, to a level of 38% by the end of 2015
- increase the proportion of deaths occurring in community settings, including in people's own homes and care homes, from 34.4% in the baseline year of 2008 to 38.8% in 2015.

What it will cost

It is difficult to work out how much money in total is spent on palliative care because so much of it is hidden within the general workload of health and social services. In Lothian, we know that specialist palliative care services cost almost £10 million (2006-07 figures). The vast majority of this was on cancer-related palliative and end of life care. In the future, we want to focus on improving value for money by, for example, following recommendations of our specialist palliative care bed review. We also want to extend high quality palliative care beyond cancer to other conditions.

Future additional investment and redesign of current resources will support the work of clinical teams. The schemes below are among the priorities for future investment which are under consideration, depending on the outcome of this consultation:

- Liverpool Care Pathway (LCP) implementation in community settings
- community specialist palliative care nurse for West Lothian
- medical staffing in the Royal Infirmary of Edinburgh and Western General Hospital to support non-malignant related palliative and end of life care
- increasing the Marie Curie Nursing Service capacity (for non-cancer conditions)
- enhanced palliative care delivery by community nursing services in Midlothian.

More information and responding to the consultation

This document is a short guide to the full strategy consultation document. The full version of the strategy contains a great deal of information, which we are confident will assist you in understanding what palliative and end of life care is, our proposed model for the future, and give information relevant to your interest or area.

We would encourage you to take time to read and consider the document when responding to this consultation.

The full strategy can be found on the NHS Lothian website at:
www.nhslothian.scot.nhs.uk/ladwinlothian

We would like as many people as possible to respond to this consultation, in order that we may hear your views on the way that we are moving forward.

There are some questions set out on pages 11 and 12. Please feel free to answer any or all of them and to add any other comments.

At the end of the consultation period we will be preparing a summary report of all the consultation responses. In this report we will list who has responded to the consultation. If you would like your response to be anonymous, please let us know.

You can respond in the following ways:

By e-mailing your comments to:
ladwinlothian@nhslothian.scot.nhs.uk

By writing to:

The Living and Dying Well
in Lothian Consultation,
Cancer and Palliative Care Programme,
Strategic Planning and Modernisation,
NHS Lothian,
Deaconess House,
148 Pleasance,
Edinburgh EH8 9RS

By telephoning: 0131 536 9057
By faxing: 0131 536 9085

The consultation runs for 12 weeks from Monday 16th November 2009 to Friday 5th February 2010.

The deadline for responses is Friday 5th February 2010.

Consultation questions

Choice (of place of death)

1. Many studies suggest that more people would prefer to die where they live, rather than in a hospital setting. Do you agree? How best can we support this?

Planning early

2. If someone is ill enough that their death in the near future would not be unexpected or surprising, then, as well as continuing care and treatment, we should be planning for 'a good death' at an earlier stage than is often the case now, perhaps as much as a year before death.

Do you agree? How might patients, their family and carers, doctors, nurses, social care staff and others involved in care best approach this?

Hospices

3. Do you think that the expertise that hospices currently bring to helping people with cancer at the end of life should be extended to help other people dying with other conditions such as organ failure (e.g. heart, liver, or kidney failure), and diseases such as dementia? How might this be done?

4. Hospice inpatient care should be for the most complex cases that cannot be managed elsewhere, and should be available to everyone, not only those with cancer. Do you agree with these criteria for availability?

5. How might hospices themselves better organise or redesign their services to make them better fit the needs of people with non-cancer conditions?

Care homes

6. Supporting care homes to provide high quality palliative and end of life care for their residents is a key aim of this strategy. How might this best be done, and by whom?

Upskilling generalists

7. The majority of palliative and end of life care is provided not by hospices or specialists in palliative care, but in hospitals and primary care by clinicians who are not specialists in palliative care. These may be generalists (for example GPs and community nursing teams, and consultants, nurses and allied healthcare professionals in hospitals). We believe that all healthcare staff should provide high quality palliative and end of life care, in all settings.

Do you agree? What support is needed to deliver reliably excellent care?

Responding to diverse needs

8. What are the key issues we need to further consider to ensure that palliative and end of life care in Lothian is provided in a way that is appropriate to the needs of the full range of diverse communities in Lothian?

Key challenges

9. Have we correctly identified the key challenges in the strategy? These are outlined on page 2. More information can be found on page 16 of the draft strategy.

Specific objectives

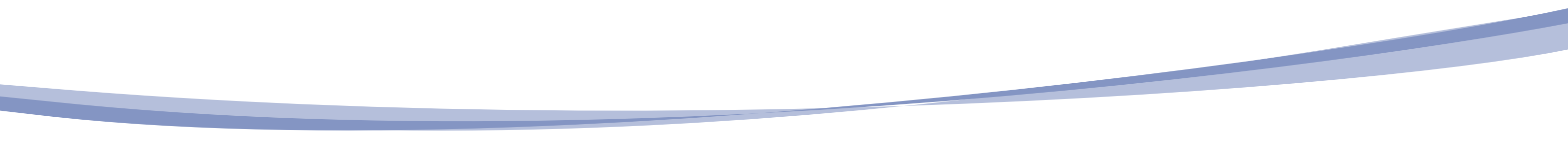
10. In the objectives listed, have we identified all key areas? Are these adequately addressed?

General

11. Is there anything else about the strategy aims, approach or objectives that you would like to comment on?

12. This strategy outlines a number of areas for improvement and development. Is there anything we are currently doing that we could stop doing?

13. Changing attitudes to death and dying may be important if we wish to get better at ‘planning a good death’. How can we encourage people/the public to have conversations about death and dying?



Copies of this palliative care strategy summary document are available in alternative formats, on request, including larger print, Braille or your community language.

Phone: 0131 536 9057 or
e-mail: ladwinlothian@nhslothian.scot.nhs.uk
for more details.

You will find this booklet and the full strategy on our website at: **www.nhslothian.scot.nhs.uk/ladwinlothian**

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