

LIVING AND DYING WELL IN LoTHIAN CONSULTATION FEEDBACK FORM

Thank you for taking the time to contribute to the development of our plan, Living & Dying Well in Lothian.

Please refer to the questions below. You do not need to answer all the questions. All responses will be considered. Please use a separate sheet if necessary, clearly indicating the question to which your comment relates.

You can download an electronic copy of this Feedback Form online from:
www.nhslothian.scot.nhs.uk/ladwinlothian

Alternatively, to be receive this file by email, please contact:
ladwinlothian@nhslothian.scot.nhs.uk

Question 1: Choice (of place of death)

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?

Our group was supportive of people having the choice of place of death if possible. The question of providing support for this option we felt was more difficult. In discussion it was pointed out that moving someone who is terminally ill to and fro from the hospital to the home setting can be disruptive and upsetting for the patient and for the family/carers and should be avoided if at all possible. This requires good communication between healthcare professionals and the family – and the resources to support the choice. The NHS and social care budgets may need to be adjusted to make this happen. We also felt that other countries and cultures may deal more effectively with the issues surrounding death – Canada and Ireland being two who may have lessons to offer us.

Individual responses from our members on this question were:-

1. “This would be better supported if there were more beds in hospices. I am shocked to discover that only 8 per cent of deaths patients die in a hospice (though of course hospices only deal with a certain kind of patient). At the same time I understand that (e.g.) the Marie Curie hospice has very few single rooms, which seems illogical since these are particularly appropriate for terminally ill patients, from the point of view of infection control as well as privacy. Funding may be a problem here.

At the same time, many people would prefer to die at home: but this requires specialist nursing: are there enough nurses available?

The aim should be to reduce the deaths in acute hospitals much further: 38% is an unambitious target. NB the figures quoted for deaths on p. 9 of the Summary document do not add up to 100%. What has happened to the missing 23.3%?”

2. “Yes. More specialist care in the community is required.

Some people do not want to face up to the diagnosis of their illness and that they will not get better and are unwilling to discuss the situation with their family and the professionals. Many people are still not willing to talk about death even although it comes to us all.”

3. “Yes, we need to respect what the patient (primarily) wants if supported by the family.

This is one time that every effort needs to be made by the NHS and Local Authority to work together with the family and/or carers to provide the patient with the individual care that they need. Professionals often appear to hold the power of ‘giving’ a choice. It would be helpful if

the ethos was promulgated that the service needs to be patient-centred – as detailed in *Better Health Better Care* – and that the emphasis was on the assumption that the patient was entitled to their dying wishes if at all possible.”

Question 2: Planning Early

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?

As with question 1, our group agreed that planning for a good death would be the way forward. However, we thought it was important that the professionals should handle this sensitively and at a pace which was acceptable to the patient and their immediate carers. We noted that the view of the Calman Report on cancer services in England and Wales (1995) was that palliative care should ‘not be associated exclusively with terminal care. Many patients need it early in the course of their disease, sometimes from the time of diagnosis.’ (p. 20) However, this depends on the patient being receptive. One of our members who has experience of running a cancer support group explained that the primary health care team is not always very well integrated into the management effort: it should, we think, have a higher profile and more respect from the secondary and tertiary sectors. In particular, there should be close partnership at the stage when active treatment ceases and the primary team reassumes responsibility in conjunction with hospice services. The cancer support group found that patients often receive mixed messages, with oncologist still apparently attempting ‘cure’ while in fact only palliation is possible: the GP is left with the unenviable task of being the bearer of the final bad news. We also noted that on a more practical issue some social security benefits (e.g. Attendance Allowance under the Special Rules) depend on the GP signing off that a patient is suffering from a particular illness or condition and has a prognosis with a limited life-expectancy (up to 6 months), so the patient will need to be aware of it when this is done.

Individual responses from our members on this question were:-

1. “This is a very important point. The problem is, both clinicians and relatives find it extremely difficult to tell the patient the truth. None the less, patients do in fact value being told the truth. This gives them the opportunity to (e.g.) make a will if they haven’t already done so, assign a Power of Attorney, see a grandchild, have a last holiday, seek spiritual support, and so on. (I base these observations on 13 years’ experience of running a cancer support group, as a counsellor. People often waste valuable energy on hiding the truth from loved ones. This can even be true of patients trying to hide the truth from carers, who think the patient hasn’t tumbled to it.)

The problem is: how to tell? ‘Breaking bad news’ training is now offered much more often in medical education: it should be routine for all doctors. It requires care, sensitivity, and time – it can’t be rushed.

It is important to keep everyone in the loop: once the patient and carer know the prognosis, all staff involved should be informed.”

2. “Yes but perhaps this might be looked upon as ‘giving up’ by the patient and they might subsequently lose their will to live even for a relatively shorter period.

Everybody will have to work together to make life easier, and perhaps more special, towards the end. The patient should not be abandoned.”

3. "I have personal experience of a dementia sufferer who developed inoperable ovarian cancer. Explaining the condition to someone who has memory problems is challenging, but if handled sensitively can be accomplished. As the patient's daughter I was able to explain what had been my mother's wishes before she developed dementia and the GP was able to put that information to her gently - and which she confirmed. I shall be for ever grateful to the expert medical doctors and nurses and carers who looked after her in her last few months."

Question 3: Hospices

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?

We were supportive of hospice expertise being extended to those with other terminal conditions. One of our group has explained that in Edinburgh, RIE nurses have and can attend courses in palliative care in its various aspects at St Columba's hospice, run in conjunction with Queen Margaret's College. Important though it is to have this theoretical knowledge, many of our group felt that the most important quality in hospice care was compassion and empathy for the patient and carers. St Columba's in Edinburgh already cares for some people who are not cancer patients – for example those with motor neurone disease.

Individual responses from our members on this question were:-

1. "Yes, hospice help should be extended to all those with a terminal prognosis, except possibly those with dementia, who may have other needs that it would be difficult to meet in a hospice setting. I have consulted a senior member of Alzheimer Scotland who agrees that hospice care would rarely be suitable for dementia patients: but they may of course, like everyone else, develop cancer. She also makes the point that people with dementia get upset if they are taken away from familiar surroundings, and are best cared for at home or in a specialist nursing home where they are used to the routine. Also, it is difficult to be precise about when they enter the terminal phase of their disease. Other diseases such as motor-neurone disease might be more suitable for hospice care. However, since hospices are 'third sector' providers, there may well be a funding crisis here."

2. "Yes certainly but the question is how in this time of strained and minimal resources. In this area there are only 2 hospices and hospitals are not really geared up to helping the dying, only the living, and can rarely cope as it is.

Also dementia patients require quite different care than those suffering from cancer."

3. "The head nurse in my Mother's care home was very firmly of the opinion that moving dementia sufferers to a different setting was generally extremely upsetting and to be avoided if at all possible."

Question 4: Hospices

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

Yes, our group thought this would be a good use of resources. Including those conditions in addition to cancer is a sensible proposal.

Individual responses from our members on this question were:-

1. "Yes, hospice care should be available to patients other than those with cancer. But again, funding may be a problem."
2. "Yes but who makes the decisions?"
3. "Complexity may not always be an issue for the patient's care, but it could be an issue for the family or carer. Partners or carers who are themselves struggling with a medical condition, or patients who are isolated by being home alone might also be considered to have complex needs. There needs to be fairly clear guidance on this to help professionals make these decisions."

Question 5: Hospices

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

Our group were of the opinion that the whole of palliative care needs to have some consistency across all services – NHS, Care Homes, etc. We thought the Care Commission would have a role to play in this.

Individual responses from our members on this question were:-

1. "The provision of single rooms would help. I understand that this is a problem in some hospices. Also of course training of staff would need to be extended."
2. "If hospices are to care for people with non cancer conditions are they to get funding from the NHS or Scottish Government? Do they have the capacity for this? Do they have the resources to care for people at home?"

Question 6: Care Homes

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?

Some care homes already work under the ethos that they provide high quality end-of-life care for their residents when the time comes. These may tend to be those provided by for example the Church of Scotland or other third party. There is much to be learned from identifying them and learning from them. We also suggest that in each Care Home Facility there should be a dedicated professional in palliative skills,(Medical or Nurse-Practitioner) who would be available on instant call to prescribe appropriate palliative medications or specialized advice when required. This would give Care Home Staff the recommended information and support to deal with their terminally ill residents without having to involve themselves with other units or organizations. This could cut out the problem of loss of valuable time or confusion caused by interactive communication problems when dealing with health personnel unfamiliar with the patient.

Individual responses from our members on this question were:-

1. "This sounds a good idea, but I have no personal experience of care homes: presumably palliative care nurses would need to be recruited and trained."

2. "Care homes would require to have a greater number and level of qualified nursing staff than perhaps they have at present. There is a cost implication in this.

At present most care homes only deal with 'ageing' patients rather than those that are 'terminally ill'. Would Macmillan nurses be able to assist in these situations and what is already in place?"

3. "My experience suggests that although care homes do deal with ageing or dementia sufferers they also care for people when that 'end-of-life' period comes. In fact, nurses and carers in the care homes can often be a source of expertise for other medical personnel since it is something they see as part of life. I'm sure more qualified staff would be welcome, perhaps funded by an NHS transfer - if fewer people are going to be in hospital to die."

4. "Care homes would require to have a greater number and level of qualified nursing staff than perhaps at present. There is a cost implication in this.

Many Care Workers who do not hold a nursing qualification have gained or are in the process of gaining a vocational qualification (SVQ 2- 4) which provides them with the skills required to care for their residents throughout their stay in the home and includes knowledge of palliative care. These particular Care Workers will not be on the minimum wage but will not be as costly as qualified nurses. After months or years within a Care Home it is these Carers working 'hands on' with the resident who will best understand the needs of the resident. A bond of trust and understanding will have developed between them over this time. Staying until the end of life within the Care Home is effectively the resident dying 'at home'.

As Care Homes are and must be run for profit there is very little slack in the ratio of staff to residents. When a resident is reaching the end of their life they will need a greater amount of time spent in making them comfortable, providing fluids, personal care, turning and so on. Perhaps additional staffing should be provided at this time to ensure the level of care is at its best. A member of the Care Staff could be allocated to devote time specifically to the dying resident. As the other Carers on duty would be attending to the other residents the care given at the end of life would be of much higher quality and less hasty. The Funding for this 'special care' could be absorbed into the general Care Home Fees if applied early in their stay."

Question 7: Upskilling Generalists

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?

In general the group thought that the key to upskilling generalists lay in improving communication skills.

Individual responses from our members on this question were:-

1. "Yes, this is obviously important. Even specialists find it difficult to tell patients they can't 'cure' them. More training in communication skills for those who have missed out (usually senior doctors) needs to be offered."

2. "Most definitely. As said above there would require to be a higher level of staffing and more specialist staff. Some people are good at the high quality care required but a lot of it cannot be taught."

3. "Perhaps one way to achieve the upskilling of generalists would be to give them a rotation in hospices/good care homes to witness at first hand how situations are handled - but only if they are going to use the knowledge and experience. There is no point in upskilling staff unlikely to use the skills learnt."

Question 8: Responding to Diverse Needs

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 the needs of the full range of diverse communities in Lothian?

The group felt that it is of paramount importance to respect patient's needs and wishes. If people have no defined spiritual outlook, then it is important to work with whatever philosophy of life/death they have if we know it or if the patient expresses an explicit wish to be treated in a particular way.

Individual responses from our members on this question were:-

1. "It is very important to make sure that culturally appropriate care is offered. At the moment there seems to be difficulty in offering such care to ethnic minorities, who may have different attitudes to death and dying from the majority. It should not be assumed that spiritual care is needed, but my own experience is that often those who are not practising members of a church or faith value spiritual support as death approaches. Volunteers with listening skills may perhaps help: but it is very important not to see this as an opportunity to preach. Patients have to find their own personal ways to say goodbye."

2. "Proper training of staff and adequate resources both in hospices, care homes and at home."

Question 9: Key Challenges

Have we correctly identified the key challenges in the strategy? These are outlined on page 6, and can be found on page 16 of the draft strategy.

Individual responses from our members on this question were:-

1. "These seem to be correctly identified."

2. "This otherwise well considered approach covers most contingencies apart from one section of the community whose sensitive and special needs have neither been included or addressed. Many individuals with severe and enduring mental health problems are now living in the community. Some, as a result of their psychiatric condition, their often poor social circumstances and continued toxic medication therapies - whose long term effects have until recently been unknown, and are known to provoke organ failure and malignancies to name but two - are statistically more likely to develop terminal conditions at least 5-10 years before the expectations of an average population. They, also, are entitled to voice their preferences when being treated palliatively and should also have the additional input from specialists who are qualified to deal with the complications exacerbated by or associated with their final illness. It has been documented amongst such

patients that if (indeed) they obtain a diagnosis when presenting with developing symptoms, it is perceived that they are unable to deal with either the knowledge of their diagnosis/prognosis or how to deal with their future care preferences. Many have neither family nor close friends and have difficulty forming trusting relationships with those around them. This is so vital for end-of-life care.

In Psychiatric hospitals, staff are not trained in the expertise of dealing with physical health conditions let alone the skills and sensitivity associated with Palliative Care. Psychiatric nurses are apparently no longer required to learn General Nursing skills within their training syllabus.

All individuals, at the end of their lives, deserve a quality of care that is as comforting as skilled palliative care is designed to provide INCLUDING the afore-mentioned patients (who, incidentally, are represented in all age groups).”

3. “The care is not only required at the end of life but also at the time when diagnosis is made. Patients need the support of the families and professionals at this time as much as at the end. This includes information on all the help, financial and otherwise, that may be available from the NHS, government (local and national) and other organisations.

Some people may require to be told quite bluntly that they need to undertake to bring their affairs into order such as drawing up wills, telling family and all the other mundane things of life.”

Question 10: Specific Objectives

In the objectives listed, have we identified all key areas? Are these adequately addressed? Have we correctly identified the key challenges in the strategy? These are outlined on page 6, and can be found on page 16 of the draft strategy.

Individual responses from our members on this question were:-

1. “I am concerned to see the proposal of even more development of an E-health computer system (p 7 of Summary document). As far as I am aware this could be very expensive and eat up resources that otherwise could be used for patient care, or professional training, both of which I see as being more of a priority than further computer systems. There is also the point that more information gathering takes front-line staff away from the job in hand. Far better to concentrate on effective communication in teams and with the patient.”

Question 11: General

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

Individual responses from our members on this question were:-

1. “This seems to be a good document, and full of worthy aspirations. If it is true that some patients with a terminal prognosis would like to die in hospital (though I don't know what evidence there is for this) then hospitals need a lot more training in communication skills and in palliative care, which is not what they are good at. It is always difficult to admit that you cannot cure a patient: but it should be seen as positive that you can still offer people relief from pain, surrounded by friends and family as appropriate, and to be gently eased along the way, in an unhurried and peaceful manner.”

2. “It may be the situation that in some cases no more treatment, particularly when expensive, should be considered if there is no realistic benefit. This does not include

painkillers etc but is it right to spend thousands or hundreds of pounds to prolong somebody's life for say a few days or weeks, particularly if the resulting quality of life is poor?"

Question 12: General

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

Question 13: General

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?

Individual responses from our members on this question were:-

1. "Education from an early age is required to enlighten youngsters on the subject of death and dying. This 'barely-mentioned' subject by virtue of the resulting ignorance, promotes fear and distaste at the thought of personal involvement in the home situation. Communities which interact and involve all age groups when dealing with all natural family events, (i.e. birth, sickness and death) are well prepared and accepting of the eventuality. This would be a building-block on which to develop a strategy of palliative care in the place of choice for patients with terminal conditions. Unnecessary involvement by paid health workers would therefore not be required and only vital support provision would mean that the total cost of homecare would NOT BE AS PROHIBITIVE as previously perceived."

General Comments

Individual responses from our members on this question were:-

1. "It should be remembered that it is not only the patient that requires support. Carers, who are often family members, may also require support throughout this period and after.

We are lucky in Edinburgh that we have the Maggie's Centre and Macmillan has just opened an information centre at the Western."

2. "It was my wife's GP that advised her to apply for DLA which at that time was refused. As you know trying to navigate through the national government information is like a minefield. It's as if they don't want you to apply or get any money to which you may be entitled. There was not at that time a simple way of getting all the information required from the one source or signpost."

RESPONDENT INFORMATION FORM

Please complete the details below and return it with your response **by Friday 5th February 2010**. This will help ensure we handle your response appropriately. Thank you for your help.

Name:	Mrs Helen Ogg, on behalf of the South Edinburgh Health Forum
Postal Address:	40 Baberton Mains Drive, Edinburgh, EH14 3BS

1. Are you responding: (please tick one box)

(a) as an individual (go to 2a/b and then 4)

(b) **on behalf of** a group/organisation (go to 3 and then 4)

INDIVIDUALS

2a. Do you agree to your response being made available to the public (in the NHS Lothian library and/or on the NHS Lothian website)?

YES (go to 2b below)

NO, not at all We will treat your response as confidential

2b. **Where confidentiality is not requested**, we will make your response available to the public on the following basis (**please tick one** of the following boxes)

Yes, make my response, name and address all available

Yes, make my response available, but not my name or address

ON BEHALF OF GROUPS OR ORGANISATIONS

3. The name and address of your organisation **will be** made available to the public (in the NHS Lothian library and/or on the NHS Lothian website). Are you content for your group's or organisation's **response** to be made available also?

YES

NO We will treat your group's or organisation's response as confidential

SHARING RESPONSES/FUTURE ENGAGEMENT

4. We will share your response internally with other NHS Lothian teams who may be addressing the issues you discuss. They may wish to contact you again in the future, but we require your permission to do so. Are you content for the NHS Lothian to contact you again in the future in relation to your consultation response?

YES NO

Please return your completed Feedback Form and Respondent Information Form by Friday 5th February 2010 by:

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

writing to:

The Living & Dying Well in Lothian Consultation
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THANK YOU FOR YOUR FEEDBACK