



Report of the January 21 meeting of the Older People's Forum in Musselburgh East Community Learning Centre, EH21 8JJ.

➤ If you receive this report in PDF format, you'll be able to click on the words highlighted in this colour of **red** to link to the relevant site in your web browser.

Who was there?

Jean Maltman	Macmillan palliative care nurse
Joyce Cattanach	Headway
Margaret Donaldson	Headway
Laurelle Edmunds	ELCCF OP joint planning representative
Ross Macphail	ELCCF MH joint planning representative
Meriel Deans	Public Patient Forum
Chris Lewis	ELC transformation team
Anne Browning	ELC transformation team
Nikki Moran	Development Officer, ELIG
Sue Green	Local Area Coordinator
Lesley Aitkenhead	Development manager, ELCCF
George Paterson	Information worker, ELCCF

In attendance:

Tom McCarthy NHS Lothian, palliative care

The main business of the meeting was a presentation and discussion of the NHS' '**Living and Dying Well in Lothian**' strategy consultation, which outlines the development of palliative and end of life care services in Lothian for 2010 – 2015.

Palliative Care is about ensuring a good quality of life during every stage of a life limiting illness from diagnosis onwards. It includes care that relieves symptoms and provides physical, social, psychological and spiritual support.

The strategy's stated aim is to extend the high quality of end of life care presently offered to those dying of cancer to *everyone* with a life limiting illness.

Presenting the strategy was Lothian NHS's palliative care Assistant Programme Manager Tom McCarthy. The strategy has been put together jointly by the NHS, Marie Curie Cancer Care and St.Columba's Hospice. Deadline for responses is February 5.

Tom distributed literature on the strategy including a **feedback form** for respondents to give their opinion on 13 questions on the strategy and the issue in general.

Jean pointed out that palliative care is not, as traditionally thought of as care during the final days of dying, but is broader in scope and includes support for such forward planning for end of life such as wills, rights of attorney or what happens to your house and contents.

Casting a shadow over the strategy is the issue of funding. Despite any best attempts by all to deliver services which are of the best attainable by, for example, reorganisation of existing resources, it's clear that in the current financial climate, the expectations of more funding are unrealistic.

Forum members talked over and discussed a number of points most often drawing upon individual experience

Some of the issues raised were:

- Cost implications: when and how is the decision made to move from service user costs and local authority paid for community care to NHS-funded palliative care.
- Age considerations: End of life care is usually thought of as an issue for older people. How well does hospital care cater for younger people or children?

- Choice of a place to die (home, hospital, hospice, care home) is a thorny issue. The strategy leans toward palliative and end of life care being delivered at home, but for some people, without adequate funds, without family or friends to support them, there is no choice and hospital becomes the sole option.
- Informed choices: Is there enough friendly and accessible information available for people to make a choice about their end of life care?
- It's the last taboo: Considering death and end of life can't fail to be subjective and a major problem is that culturally, socially, and individually, people feel a great reticence in approaching the issue. Some central government initiative in engendering change is needed.
- Medication out of hours is hard to come by: There currently no out of hour pharmacies available in East Lothian to dispense general medicines, let alone those for palliative needs. There is a job of work in changing the mindset of pharmacists and GPs to be proactive rather than reactive.
- The response service highlighted in the Older People's Strategy must be up and running if the services implied in the Living and Dying strategy are to work. (This includes obtaining drugs as mentioned in the last point.)

The meeting continued aftertime in small groups, after which Tom compiled responses and issues voiced in a copy of the strategy feedback form. **A copy** (*click to download*) of this is included in this posting as a separate document.

.....

The time and form of meetings of East Lothian Older People's Forum have changed.

We're now hoping to have themed meetings raising pertinent issues. The time and date of the next meeting will be decided shortly.