

We need to talk about Palliative Care

NHS Lothian

The response has been informed by our acute hospital specialist palliative care services, and by community based palliative care services. Responses from each perspective are indicated for each question. Provision of feedback to the committee has been co-ordinated by the Lothian Palliative Care Managed Clinical Network (MCN) – any questions or follow-up to be addressed to the MCN Chair in the first instance:

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Under separate submission to the committee, Lothian Independent Hospices have also provided feedback to the inquiry.

1. What has been your experience in terms of access to palliative and end of life care?

Acute Hospitals

- People with *any* advanced illness can be referred for a *specialist* palliative care assessment by the team providing their *general* palliative care.
- Specialist palliative care advice (usually from a consultant) is available by telephone to teams working out-of-hours in hospitals and the community across Scotland. This service is more difficult to sustain in areas where there is a single-handed palliative medicine consultant.
- Face-to-face assessment by a palliative care specialist is not available 7 days a week – there are too few palliative care specialist staff available to provide this service in the community and all acute in hospitals.

Community

- Those with cancer diagnosis have to date had easier access, though there have been some improvements in relation to those living with non malignant disease and multi-morbidity.
- Generalist care is provided using the palliative care approach but this is not explicit – i.e. a community nurse may not say '*I am here to give you palliative care*'
- Often people, and those who matter to them, do not realise they are receiving palliative care because they are not under the direct care of a palliative care specialist team or dedicated service such as the Marie Curie Nursing service. However those delivering their care may be using the palliative approach.

- Direct access (face to face contact with person and those who matter to them) to specialist palliative care is available Monday –Friday office hours. Telephone advice is available via on-call 24/7 and there are occasional home visits by palliative care consultant out of hours.
 - Formal links to specialist palliative care are less visible to community based hospitals.
 - Within Lothian, access to support for those in prison has improved but still needs significant work due to the increase in the elderly prison population and those living with multiple co-morbidities and lower life expectancy.
- 2. How could it be ensured that access to palliative and end of life care is equitable and available in all areas and for all types of terminal illnesses?**

Acute Hospitals

- Telephone advice from a palliative care specialist nurse supported by a consultant should be available 24/7 throughout Scotland. This could involve new models of working across Boards supported by access to patient electronic records to make it sustainable for the professionals involved, cost-effective and safe.
- All clinical teams in the community and hospitals should be able to provide good generalist palliative care for their patients who have advanced, progressive illnesses.
- The Scottish Palliative Care guidelines support good practice in symptom control and all staff should be able to access and use them.
- Training should be provided at all levels – (see Q8)
- Specialist palliative care services need to be available to support general palliative care in all care settings for situations where the needs of patients and families are complex and cannot be managed by the current care team. Some patients will need a single assessment by the palliative care specialist, a short period of care with several visits, or phone contacts, or an admission to a specialist palliative care bed in a hospice or NHS Palliative Care Unit.
- It is important to resource adequate specialist palliative care services in hospitals as well as in the community because many patients with non-cancer illnesses are first identified as having palliative and end-of-life care needs during a hospital admission. Hospital palliative care services are particularly well placed to offer specialist advice and support for patients dying with all types of advanced terminal illness as most people have at least one acute hospital admission in the last year of life. Approximately 30% of inpatients in an acute hospital in Scotland

will die within a year although it is difficult to predict accurately which individual patients will die or when.

Community

- Supporting public awareness of what is meant by palliative care, who is involved in delivering palliative care, and the benefit of discussing what matters to them now and if their condition was to decline.
 - Earlier recognition by health care & social care staff as to when a person may be at risk of dying and therefore would benefit from supportive and palliative care approach, using tools such as the SPICT (www.spict.org.uk), and resource such as Difficult Conversation Booklets (Dying Matters).
 - Community services (GPs, community nurses, social care) need to be adequately resourced; there is often the skills, willingness but not the time to be involved in the earlier discussions regarding what and who matters.
 - Specialist palliative care needs to be resources to support generalists in all settings, for situations where the needs of patients and families are complex and cannot be managed by the current care team. There should also be enabling opportunities to shadow specialists so staff can be more confident and competent when dealing with a similar situation in the future.
 - Recognition of the increasing role community based hospitals and care homes play in caring for people and those who matter to them, who will all have palliative care needs.
 - Testing of new models / ways of working to support earlier identification and engagement – peer support, Dr to Dr type letters.
 - New measurement tools which focus on patient outcomes .
 - Macmillan Cancer Support & SPS discussing national senior nurse post.
- 3. Can you identify any areas in terms of access to palliative and end of life care that should be focused on as priorities?**

Acute Hospitals

- Equitable access to palliative care telephone advice and a specialist assessment for patients in all care settings – community, care homes and hospitals. It should be possible to set standards for equitable access by working this out for each hospital (based on approximately 30% of the beds) and each community area (based on population data – usually about 2%). Palliative care nurse specialist time and palliative

medicine consultant sessions per bed or head of population can be calculated.

- A broader focus on care of people whose health is deteriorating such that they may well die in the next years and months, as well as on care in the last days of life, will ensure more people who could benefit from holistic needs assessment and future care planning receive it.
- Less emphasis on place of death as the primary outcome measure is important because for many people the 'right' place becomes evident when they are dying and not in advance.
- More focus on helping patients and their families live as well as possible with advanced illnesses. This means looking at what matters now and planning for changes in health or care needs. People want to maintain normality as far as possible and many can find their own solutions if they get the right support and advice from professionals and services.
- Less focus on just 'planning for dying' which usually involves asking people to choose their place of death in advance - if their illness journey is unpredictable (this is often what happens) a choice has no real meaning for them and may not be a realistic option anyway. Some people do not want to think about 'place of death' in advance as it is distressing, but talking about what we could do if the patient got more unwell or their care needs change is much more helpful for them.
- Even with the best of anticipatory care planning some patients will deteriorate rapidly and unexpectedly or delay seeking additional help with activities of daily living until their care needs cannot be met in the community. More needs to be done to provide rapid access assessment of new clinical problems reviewed alongside the patient's anticipatory care plan and rapid response care packages. These care packages should be available on the basis of need not diagnosis or prognosis.

Community

- Community services (GPs, community nurses, social care) need to be adequately resourced; there is often the skill, willingness but not the time to be involved in the earlier discussions regarding what and who matters.
- Testing of new models / ways of working to support earlier identification and engagement – peer support, Dr - Dr type letters.
- Increased access to specialist palliative care support at weekends / public holidays, across all settings.

4. When is the right time to begin discussing options for Palliative Care, who should be party to that discussion, who should initiate it and where should it take place?

Acute Hospitals

- Identifying people whose health is at risk of deteriorating or is now deteriorating is essential if timely discussions are to be offered. We use signs of poorer health that can be recognised easily by professionals, patients and carers – the Supportive and Palliative Care Indicators Tool (www.spict.org.uk) – to help prompt these discussions.
- Palliative care is sometimes still seen by professionals, patients and families as only being relevant when a patient is clearly dying and/or there are few or no other treatment options for their advanced illnesses. This needs to change. People may well have unmet supportive and palliative care needs while still receiving other treatments and it is very difficult to tell in advance how or when a person with one or more advanced illnesses will die.
- Continued public awareness about future care planning is important and helps more people choose a Power of Attorney. More support and help for people who are taking on being a POA is needed.
- Everyone should know about the Key Information Summary (KIS) and people should be encouraged to ask their GP if they need one. Public awareness campaigns could help. This might allow the GP or practice nurse to open up conversations about future care planning more generally.

Community

- People who may benefit from palliative care approach should be given the opportunity to discuss what matters to them, who matters to them, help to plan for the future, and to have a 'plan B'. Not everyone will wish to take up this opportunity however it should be made clear that if they change their mind they can come back and discuss.
- The discussions could be initiated by the professional, the patient and / or someone who matters to them. It is important that these discussions are recorded and available to those who may be involved in care in / out of hours to ensure they can influence care decisions / support achievement of the patients preferred outcomes.
- The discussions should take place in a setting that the patient is comfortable and feels safe in.
- Testing of new models / ways of working to support earlier identification and engagement – peer support, Dr Doctor type letters,

- Wider public engagement / media campaign to raise awareness and prompt people to share / discuss what they are thinking with those who are caring for them
- 5. What works well in discussing palliative and end of life care and how is good practise communicated? Where do the challenges remain?**

Acute Hospitals

- When people are identified as likely to benefit from a holistic palliative care assessment that assessment needs to happen alongside the continuing management of their other health and care problems. Professionals who know the patient and family need to start with finding out what they know, what they are expecting, and what matters to them. People's goals are then used to help us make the right treatment and care choices together.
- It is important to understand and respect the different ways people cope with serious illness. Some people want detailed information and to plan ahead. Others find this too distressing and want to focus on managing from day-to-day. Skilled communication allows these people to hope while planning 'just in case'.
- It is very important to avoid 2 things in discussing palliative and end-of-life care:
 1. Talking about 'trying' a treatment that will not work or have a very poor outcome or using words like 'the chances' of the treatment working. This can make people think they have to take any chance and not give up so they may choose a treatment that will do them more harm than good.
 2. Using negative words like 'futility', 'ceilings of treatment/care' or 'treatment limitation' which can be understood as meaning people are being neglected or are not receiving treatment and care that should be provided for them.

Community

- When the person providing the care, and the person receiving the care, are on the same page.
- When discussion takes place between professionals and the person (and those who matter to them) as part of ongoing care.
- Honest and open conversations about predictable vulnerabilities, and the inability to predict when these may occur and therefore why it would be better to have thought about them and what would like / need to do, and what plan B would look like.

- Hope versus false hope – how to manage uncertainty.
- Fear of some clinicians in having the conversation, as this may upset whom – the person, those they care for, or themselves.

6. What is the role of anticipatory care plans in supporting Palliative Care discussions and how can their uptake be improved?

Acute Hospitals

- Planning for getting ill is less distressing for many people than 'planning for dying'.
- Having a universal electronic anticipatory care planning record (Key Information Summary – KIS) is a huge improvement and this tool needs to be used to its full potential. This means it must be accessible to all services and regularly reviewed and updated. The tool itself needs to be improved as the current template is not ideal.
- Hospital discharge processes need to connect effectively with the KIS so that information is transferred via email to the GP practice on the day of discharge, acted on and uploaded to the KIS

Community

- Life-long discussions and planning should be the norm not the exception – focussing on key stages: financial independence, long term relationship / marriage, parenting, property ownership, ill health, writing a will, obtaining power of attorney, and funeral wishes.
- Those with long-term conditions should be encouraged to develop an ACP / self management plan to promote health & wellbeing, but also to recognise uncertainty and document wishes if their condition was to deteriorate. This is especially pertinent to those who are at risk of cognitive impairment.
- Those nearing end of life should be given the opportunity to review what matters, and who matters.
- Health Promoting Palliative Care, GLGDGG, To Absent Friends Week, Compassionate City, Media and advertising e.g. Australia

Groundswell Project 2105



- There is also a need to ensure that the KIS and ACP templates consider more carefully the specific needs of Children and Young People to support effective use of ACP / KIS completion by those involved in co-ordinating the care of children and young people.

7. How should information about Palliative Care be made available to patients and their family during any initial discussions and how easily available is this information?

Acute Hospitals

- Public awareness about palliative care has focused on death and dying and is not as well integrated as it could be with information about living as well as possible with poor and deteriorating health. Some charities have produced good materials for people with dementia, heart disease, motor neurone disease etc that cover the whole illness journey and these are helpful and should get more publicity.
- People should be aware that palliative care is provided by all clinical teams who can call on additional specialist involvement as and when that is needed. Specialist palliative care is not always understood as complementing care provided by many others as is the case with other specialist services like cardiology or renal medicine.
- Palliative care is about focusing on quality of life and people's goals and managing their underlying conditions as well as possible while accepting that the underlying causes of a person's deteriorating health cannot be cured/reversed. This is not well understood.

Community

- Information both verbal and written is required – leaflets, booklets, books, internet, NHS Inform, third sector.
- Need to consider how ready the person is to hear terms such as 'palliative care' especially during initial conversations. This does not

mean important issues should be missed such as discussing issues related to thinking about the future, dealing with uncertainty, anticipatory care planning.

- Good resources such as having difficult conversations are available, some online and other both online and hard copies. There is often a cost associated to these resources and this limits access for health care professionals and patients / carers. Majority of resources are available in English and not in other languages.
- There is often very good information / resources available via youtube however this is a resource many NHS staff cannot access within their work / on NHS computers. This reduces access to support direct patient care, and training / education.

8. What training and support is provided Health and Care staff on discussing Palliative Care with patients and families and are there any areas for improvement?

Acute Hospitals

- Education is improving but there is still much to do in a health system that is still dominated by a disease-focused rather than person-centred approach.
- A mixture of online learning resources, apps and written materials allows staff to learn in their own time and have information to hand when working with patients. Face to face teaching is best delivered in smaller, interactive groups able to use case-based learning and simulation for palliative care teaching and enhanced communication training.

Community

- Training is available for health & social carers, however how to have difficult conversations has not been a core element of some of this training.
- The main issue is often getting staff released to attend training.
- A blended approach is required as much of palliative care is self awareness and communication related
- Training sessions where staff from different care settings attend together can be invaluable – this increases awareness of each other's perspectives and services available, & provides networking opportunities.
- More research and patient experience work is required to support development of services and support learning. Personal story is a very powerful teaching aid.

9. How do Health and Care organisations ensure that the discussions about palliative and end of life care are taking place at the right time?

Acute Hospitals

- High quality, participatory research with service users and inclusion of patient/family experiences and perspectives in any service improvements are an essential part of all future developments in palliative care.
- More needs to be done to explore people's experiences of the emerging evidence base about sensitive and effective ways of opening and continuing conversations about palliative and end-of-life care. This includes looking at public awareness as well as evaluating experiences of care and the support and education of professionals.
- There is good legislation to support best practice in making decisions with people whose capacity is affected by advancing illness but more needs to be done to ensure this framework is used as well as possible in clinical practice. Capacity fluctuates and an approach that involves those who are close to the patient as much as possible is important. These people will experience loss and then bereavement and how they are involved, cared for and supported before the person's death can have a big impact on their future health and wellbeing.

Community

- At present the majority of work is about increasing awareness of the importance of having these conversations and then recording / sharing and supporting staff to be Conversation ready

10. What are the challenges in recording and documenting Palliative Care priorities and how well are those priorities communicated between different health and care providers?

Acute Hospitals

- Optimising use of electronic patient records will help professionals and teams to document anticipatory care plans and these should include patient goals and priorities and be updated over time.
- Personal emergency care plans are important and need to include actions for informal carers and a personalised plan for what treatments will be of benefit in the event of the patient deteriorating and in line with their goals. These should form part of the anticipatory care plan in all care settings.

Community

- The different IT systems in use across NHS & Social Care presents challenges to communication
- Priorities are dynamic and may change according to circumstance, condition, and the needs of those who matter to them. Any system for recording needs to be updated as priorities change.
- KIS has made improvements however there is still a way to go - supporting staff in the different settings to access KIS, and to share with GP practice when there have been changes e.g. post admission / hospital appointment.

NHS Lothian