

We need to talk about Palliative Care

Anonymous Submission

I submit the following responses:

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

My father was diagnosed with terminal cancer and access to end of life care was arranged by NHS Lothian. My experience of the end of life care provided to my father was totally unsatisfactory.

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?

All NHS medical staff and General Practitioners (GPs) should be able to inform patients and their relatives of the availability of palliative and end of life care. Information on how to access these services should be clearly displayed in GP surgeries and within all Hospital premises.

3. Can you identify any areas in terms of access to palliative and end of life care that should be focused on as priorities?

I don't have any points to add in relation to this question.

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?

The time to begin a discussion around Palliative Care is when a patient is diagnosed with a long term degenerative or terminal illness. These discussions should involve the relevant medical practitioner, the patient and their relatives/carers to ensure that all parties have an opportunity to discuss the options available. The discussion must be initiated by the medical practitioner but all interested parties should be involved in this. This also means that all parties have a clear understanding of what has been agreed in relation to future treatment.

The venue for these discussions will depend on the individual circumstances of each patient.

5. What works well in discussing palliative and end of life care and how is good practise communicated? Where do the challenges remain?

There are issues regarding the level of engagement between medical practitioners and the patient and their relatives for end of life care. Decisions are taken by medical staff without consulting the patient or in instances where the patient is unable to give consent, their relatives. It is critical that their relatives be consulted prior to any fundamental changes to the patient's end of life care.

The lack of involvement of patients or relatives in decisions regarding end of life care was one of the major flaws of the now discredited Liverpool Care Pathway (LCP). There are already concerns¹ being raised about the new guidelines issued by the National Institute of Health and Care Excellence (NICE) for hospital staff in England on end-of-life-care. It is vital that the patient and their relatives are consulted before changes to treatment are implemented to maintain any level of trust in the medical profession.

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

It is fundamental that there is an honest, open and transparent discussion between the patient and the medical practitioner regarding the purpose of an anticipatory care plan. The Liverpool Care Pathway (LCP) was the perfect example of the medical profession deciding on its terms how a patient's care should be managed. I note that the current ongoing consultation by NICE on 'Care of the dying adult' only appears to be open to the medical profession and other associated groups. This is unacceptable given the many failings of the LCP and the unnecessary suffering which it caused to many patients and their families. The medical profession must be accountable to patients and their relatives to avoid a repetition of the LCP.

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?

Information on Palliative and end of life care should be made available in hard copy so that the patient and their family can refer to this information prior to the initial discussion taking place. The information should also be available on all NHS Health Board websites.

In my experience, we were advised by the Hospital that my father's case information had been passed onto a Hospice and we would be contacted by a Hospice nurse to arrange an assessment at home. We were not issued with any information relating to end of life care when my father was discharged from Hospital.

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

I am unable to provide any comment on the current training and support which is provided to healthcare professionals in relation to Palliative and end of life care.

However, I would like to re-emphasise the importance of ensuring that the patient and their family are consulted prior to any fundamental changes in the patient's treatment.

¹ [New NHS death guidelines 'worse than Liverpool Care Pathway'](#). The Daily Telegraph, 3 August 2015.

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?

It is difficult to determine the correct time as each patient is unique but priority must be given to ensuring that all parties are involved in these discussions. The patient and their family must be at the centre of any discussion relating to Palliative and end of life care.

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?

I don't have any specific points to add in relation to this question but it is imperative that patient records are kept up to date and complete.

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