

We need to talk about Palliative Care

Grampian Palliative and End of Life Care Network Core Group

Organisations and individuals are invited to submit written views to the Committee in relation to the inquiry remit. Those submitting views should feel free to address the issues in whatever manner they prefer, but it would be appreciated if they could attempt to address the questions set out below—

It is not clear whether this refers to general or specialist palliative care, or both. The same issue is present with the term ‘end of life care’ due to differing definitions and interpretations that have been applied. Such differences in interpretation are likely to cloud responses.

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

Access is variable, dependent on the definition of access. All patients in the community have access to general (non-specific) palliative care from their primary care teams, though this is not a proxy indicator of the quality that they may receive. Palliative and end of life care should be delivered by clinicians in any clinical environment, with the additional support of the specialist service. The education programme organised via the Grampian Palliative and End of Life Care Network has helped build relationships between generalists, both in hospital and primary care, and the specialist service. NHS Grampian has a Hospital Specialist Palliative Care Team (HSPCT) Monday to Friday 8am – 5pm, alongside 24 hour telephone advice for professionals from the specialist unit. A Clinical Guidance Intranet (CGI) is in place for written advice. An outpatient service is offered for primary and secondary care referral. There are 21 inpatient beds and a day unit provided by the specialist service at Roxburghe House, accounting for approximately 4% of deaths annually.

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?

Accessibility should be based on clinical need, not diagnosis. There needs to be a properly staffed 24/7 service with access to planned respite. There is a need to ensure general clinicians are up-skilled in the use of recognised tools for identification and assessment, which indicate disease progress and decline, to therefore be confident with continued access to advice and support from the specialist service.

3. Can you identify any areas in terms of access to palliative and end of life care that should be focused on as priorities?
 - **Comprehensive Out of Hours (OOH) service;**
 - **Engagement around understanding of what specialist palliative care provides;**

- **Focus around how people access palliative and end of life care and how their needs are identified;**
 - **Planned respite care;**
 - **Non-malignant, dementia and frailty trajectories;**
 - **Care at home.**
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 problem with this question is that it appears to make palliative care look ‘binary’ – there is no one person or ‘right time’. Palliative and end of life care is complex but must always be focused on the individual. There is a need to consider deterioration in the context of general health to begin to discuss uncertainty and understand expectations. In addition, great care has to be taken about ‘options’ as real choice may be limited. In succinct terms, there is no single answer.

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

Forming good relationships for good communication is absolutely essential, as is the need to attend to sensitivity, compassion and attitude of individuals. It is often the ‘little comments’ that are made which can be so damaging. The use of targets, Quality and Outcomes Framework (QOF), Directed Enhanced Services (DES), etc, however, can at times lead to inappropriate “hand offs” and unnecessary interventions for patients. The challenge is to encourage professionals not simply to follow processes/structures in a ‘tick box’ fashion.

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

The theory of Anticipatory Care Plans (ACPs) is valid and may be helpful in determining patient choice. However, individuals can and do change their minds when a crisis is looming so there is a need for flexibility and review. A ‘plan B’ is crucial. In addition, if the information is shared (with consent) with other relevant individuals, particularly OOH services, but not accessed or ignored, then they are futile.

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?

This is a semantic issue and highlights one of the issues about how palliative care is defined. The focus of care should be on maximising wellbeing and quality of life and minimising symptoms. Perhaps the conversation should be more open about care not cure. NHS Inform does have some information and in Grampian, the Grampian Palliative and End of Life Care Network Partnership Group is looking at

developing a 'patient charter' type document as a starting point to help empower patients and carers to raise the issues/ask these questions.

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?

Engagement by secondary care is the main area for improvement, as well as the need for more generalist care, especially as people often have more than one illness/condition. Making palliative care a specialism has de-skilled many general clinicians. Time to allow staff to be released to attend training is a growing concern. In Grampian, there are a number of training sessions offered on identification, creating rapport and reflecting on practice (Principles of Palliative Care; Fundamentals of Palliative Dementia Care) though the education resource is currently under review. Education and training should be mandatory in this field of clinical practice.

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?

Organisations do not – it is the individual professional's responsibility. There is no generic right time – it will be dependent on the patient. Increasing a clinician's ability to recognise deterioration and encouraging self awareness to have compassion are essential but not amenable to measurement.

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?

Priorities are recorded in anticipatory care plans and key information summaries, capturing patients' wishes, but key is ensuring all staff have access to the system, are able to use it and see the value in its use. There is a danger that care is becoming increasingly fragmented and uncoordinated.

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