

We need to talk about Palliative Care

East Dunbartonshire CHP

The Views of Community Nurses

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

One of the biggest challenges to accessing palliative and end of life care is identification of need. We may not be getting identification of palliative care needs right for a large number of people with non-malignant disease due to a number of factors; reluctance of patients with organ failure to accept palliative nature of disease, unpredictable trajectory of illness, frailty, confidence of medical / nursing staff to have conversation re palliative care needs. When someone is identified, generally access to palliative and end of life care is good, this has developed in the last 10 years, palliative care services are available to all regardless of diagnosis when previously non-malignancy excluded some people accessing services such as hospice etc. Recognition of end of life care can be challenging particularly for patients with dementia, COPD and heart failure and so they may not access all the support they require because of this. Active treatment in terms of chemo/radiotherapy can continue when someone is very near end of life with limited benefit and often a negative impact on quality of life because they and their families may not be fully informed or not fully understand the limited benefits of accepting or continuing with treatment. Staff may be reluctant to have the difficult conversation around prognosis and/ or the patients reluctance to accept this.

The increased aim for people to be able to die at home is positive, though there are times when due to specialist palliative care needs or a desire not to die at home, other options should be available. This requires sufficient Hospice places or potentially, appropriate NHS locations that can offer a similar setting.

In the community setting multi-disciplinary palliative care meetings within the GP practice is crucial to supporting people and their families with palliative and end of life care needs, District Nurse input is central to this and intervention an early stage is crucial to support holistic care management .

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?

Consultants/nurse specialists involved in diagnoses have to have the conversation around palliative care with patients and pass that onto GPs. GPs and other health professionals in the community have to improve recognition of people with palliative care needs particularly frail elderly people with limited support. More or less all the population has a GP, and therefore a District Nurse, who together can lead the delivery of care identified in the community setting. This can be done via Gold Standards Framework for Practice meetings

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

Recognition of needs, patient carer feedback. Public health campaign to get people talking about death and dying in a way that is supportive. Proper, regular, GP Gold Standards meetings should be seen as routine practice and not just best practice

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?

consultant/GP/specialist nurse when people are newly diagnosed with any disease that is palliative. The patient and anyone they would like to be present, should be in an appropriate setting i.e. Quiet confidential areas must be available in acute clinic and ward areas. The information re the discussion should be passed to the GP. In the community GPs should have the conversation with patients whose condition is palliative, DNs often have the conversations with patients as their disease progresses and whose needs are becoming end of life as they will often know the person best.

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

Demonstrate care and compassion. Being clear and honest, highlighting what can be done, identifying supports and arranging to meet again to go over and answer any questions that may not immediately be there. Challenges remain with patients/carers not wanting to receive/believe information in the first instance. Definite follow up plans should be made which may be just to discuss it all over again.

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

Involving the patients views should be crucial to anticipatory care plans and red flagging changes that may occur so that people seek early support. All patients should be offered a My Thinking Ahead and Making Plans leaflet to encourage them to consider what's important and to allow them to communicate this to health professionals.

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?

Patients and families all have very individual requirements for information, what is essential is the identification of who can support them and how to contact them. Professionals should have a range of tools and supports available to offer in each specific instance.

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?

Training and support within Greater Glasgow and Clyde is available and good for community nursing staff.

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?

Multi-disciplinary communication, palliative care meetings within GP practices as highlighted in questions 2 and 3

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?

Use of modern IT systems is important. Access to patient records in the OOH period or in A/E. This may be the key time for an ACP to be enacted.

General Practitioner Perspective

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

We have good local access to Hospice care, but not always guaranteed a bed when required, potentially require to admit terminally ill patients to an acute in-patient bed when in fact they would be far better placed in a hospice bed. Sometimes admission is the only option when symptoms prove difficult to manage, or when the patient and carers/ family are failing to manage despite maximum support. More hospice beds, adequately funded through the NHS would greatly help the matter.

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?

This is likely to prove impossible, in order to provide cover to more rural and remote areas. Within cities this is easier to manage. Remote and rural areas may have access to local cottage type hospital beds, but in order to ensure adequate care, local staff/ GPs etc would need to have appropriate training in end of life care, and get enough support to deliver this confidently.

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

Issues around dying at home for those patients who do not have family or friends in the position to provide care.

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?

This is impossible to define - very much depends on the individual patient, relationship with the GP/ Care provider. Also issues around ongoing secondary care intervention and discussions by oncology etc which may suggest to patients that they have more time left than is actually the case. Our experience is that our secondary care colleagues find it hard sometimes to tell the patient that there is nothing more which can be done. Discussion should involve the patient, family members and care providers - this needs to be communicated to all staff involved in care - community nursing, social work, secondary care colleagues, palliative care teams. Ideally these discussions should be somewhere that is comfortable for the patient, preferably in the home, but could be in a hospital ward, but need to ensure privacy and comfort for the patient and family to take on board the issues discussed.

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

Knowing the patient well, having a relationship with them. Using non-medical terminology and being honest. Need to use correct language and avoid euphemisms e.g. the tumour, the mass, nearing the end - be open, talk about cancer and dying - this avoids any confusion, and can still be done with empathy and compassion. Need to allow the patient to ask questions and check their understanding of the discussion. Challenges - not everyone is a good communicator, finding the right time - not always easy to determine when the patient is ready to have this discussion.

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

ACPs - allow the concept of planning for what might happen to be introduced and allows sharing of information to be agreed at an earlier stage - patients often glad to know that staff in A+E, Ambulance services and Out of Hours will have access to information, so they do not require to constantly repeat their story.

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?

Written information to back up verbal discussions would be very helpful. Not currently aware of any leaflets or info used locally.

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?

Unable to comment for all care providers - within General practice, regular update meetings can be attended, continual professional development meetings, active Palliative care MCN locally send out updates.

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?

Patient feedback - need honest feedback from patients and carers to ensure we get it right - BUT need to make sure we ask the right questions.

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