

We need to talk about Palliative Care

NHS Western Isles

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

- a) *Varied. There is still misunderstanding even within the healthcare community about the term 'palliative' particularly for people without a cancer diagnosis. Some people still think that 'palliative' means that a person is actively dying and at absolute end of life. For people with palliative and end of life care needs who are known to the Macmillan Nurses, they have strong advocates in those nurses to have their wishes heard and acted upon whenever possible.*
- b) No personal experience
- c) Often the most rewarding part of a GPs' work, if not also the most intensive

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?

- a) *There needs to be a better understanding of who would benefit from that care. Recognising when someone is dying is not easy but could be better. People who are dying from cancer usually have a fairly predictable decline but for other conditions this is not so predictable.*
- b) That clarity is provided to the public (and probably other staff) on all those staff and teams that provide end of life care, who can refer to them and the outcomes provided to measure availability of the care required
- c) standard referral routes. However, every area is geographically different, patient expectations are different which might result in service provision being different

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

- a) *Bringing the quality of care for people with non-malignant conditions up to the same as for people with cancer. Adult hospices still have a disproportionate number of patients with cancer compared with other conditions – don't know if this is because the non-cancer patients are less likely to be referred for hospice care.*
- b) That clarity is provided to the public (and probably other staff) on all those staff and teams that provide end of life care, who can refer to them and the outcomes provided to measure availability of the care required
- c) Greater awareness of non malignant palliative conditions

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?

- a) *Very, very sensitive subject. Right time? When cure is not an option and the patient has been told that and understands that (NOT the same thing!) Party to discussion? Patient (if has capacity), family (with patient's consent) and professional who has best relationship with them (not always the senior member of the healthcare team) Initiate the discussion? It depends. It could be the patient or family member. If it's the professional, timing of it needs to be very sensitively handled. They must have good, highly polished communication skills. Where? In a quiet, private place, free of interruptions.*
- b) When the patient deems it fit. I think we need to get better at appreciating what the patient wants and working with them not round them. Whether prognosis is for a short or long period, patient should be made aware of what is available to support them either psychologically or physically....then it is up to them to instigate that though periodic communications should be made just to check by an identified named person
- c) Often the GP. With provision made for place (patient on their own?, having to travel back home on their own? Is a house visit more appropriate?...) and who might accompany the patient.

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

- a) Good honest relationship with patient and family that encompasses trust. For professionals learning: using case histories and discussions have been good and felt 'safe' for the participants, i.e. not the real thing. Challenges? Fear of saying the wrong thing so avoiding the conversation totally.
- b) Highland provide a newsletter which is really good for providing general information. We could include more in our weekly team briefs as we don't really have a forum for disseminating good practise?
- c) An integral part of GP training and key part of current undergraduate medical education.

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

- a) Think the first part of the question is the wrong way round. I think the ACP only comes into play after the palliative care discussions. Keeping the ACP up to date is essential but access to it can be fragmented, i.e. if on the GP's recording system, it isn't available to others, even essential folk like Macmillan Nurses.
- b) ACPs very important and some GPs are excellent but requires to be more widespread and staff having access through KIS. Staff require to be aware that ACPs are available within KIS
- c) Key role

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?

- a) Verbal initially and with great sensitivity. Ascertaining from patient and family if they'd like any written information to back up the conversations. Macmillan produce good booklets. NHS Inform's palliative care page is also useful.
- b) Ask the patient

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?

- a) Healthcare staff have provided educational sessions for home carers about the 'normality' of dying. There are always areas for improvement!
- b) Don't know

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

- a) There is no formal structure for this locally.
- b) Don't know

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

- a) Access to different recording systems by health and social care staff. Phone calls still help thankfully!
- b) Not aware of any unless a risk assessment is raised where priorities are not being met
- c) Issues around shared record – currently for housebound patients receiving home care and health care, there is a shared record which is placed in the patient's home.
- c MDT meetings attended by GP, Community nurse and home care organiser
- c Challenge is to develop the shared record – part of the NHSWI eHealth action plan

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