

We need to talk about Palliative Care

NHS Forth Valley

Feedback from Forth Valley MCN

Question	Response
<p>1. What has been your experience in terms of access to palliative and end of life care?</p>	<p>A wider source and variety of support than ever before is now available with Day Hospice, Outreach and home settings available and a broader range of conditions now eligible for treatment</p> <p>Access to palliative care is generally good when it has been identified as a need. Unfortunately there are circumstances where palliative care is accessed late. This can be for a number of different reasons but includes:</p> <ul style="list-style-type: none"> unrealistic expectations from healthcare staff that the period of time over which the patient may decline, or less commonly, that they will make a full recovery, a focus on active treatment despite obvious decline, lack of use of prognostic indicators, staff avoiding discussing palliative care due to lack of confidence. <p>Access to Hospice care can on occasions be limited by the capacity of the local hospice. They use criteria to prioritise patients based upon need.</p> <p>Access to specialist palliative care nursing is unavailable in hospital at the weekends. Cover for community hospitals is also significantly less than the acute hospital.</p> <p>Where 'Hospice at Home' and 'Marie Curie' services are available for</p>

Question	Response
	<p>people dying in the community, they are well received. However it can be difficult to put these in place at short notice and the hours provided are sometimes less than is required.</p> <p>Care homes routinely support people nearing the end of life, but can have inexperienced nursing and care staff. It is more difficult to get specialist palliative care input when someone is in a care home.</p>
<p>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?</p>	<p>Through:</p> <ul style="list-style-type: none"> - Clarity about what palliative care is - public information campaign to highlight role and range of palliative care available and who provides it . - 7 day a week specialist palliative care expert cover in hospitals (this could be through a network approach). - audit access to palliative care - a shared approach between NHS and Voluntary Sector - any professional (health and social care) who meet people with “palliative needs” at any stage in the illness journey are competent at addressing issues or signposting to someone who can. <p>At present professionals are the gatekeepers to palliative care services. More informal access at an earlier stage promoting a more ‘self-management’ approach should be developed.</p> <p>Palliative care needs to be integrated into clinical pathways for all disease</p>

Question	Response
	<p>groups to prompt timely involvement.</p> <p>Palliative care needs to be embraced as part of regular community based services and become more proactive, pt/community led rather than only reactive.</p>
<p>3. Can you identify any areas in terms of access to palliative and end of life care that should be focused on as priorities?</p>	<ol style="list-style-type: none"> 1. The palliative care needs of those in Care Homes 2. Out of hours access to palliative care in community 3. 7 day a week access to palliative care expertise in hospitals 4. Access to professional carers to support end of life care at home 5. Access to palliative care for people with non-malignant disease at appropriate stage of illness journey, not only at the end of life. 6. Training to raise awareness, skills and confidence of all staff
<p>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?</p>	<p>There is no “right time”, this depends on the individual and the supporters around them. Discussions about palliative care should be sensitively discussed with anyone who has a chronic progressive long term condition. Having the discussion does not negate the option for active appropriate management of their condition.</p> <p>All health care staff involved in patient care should have some skills in recognising the need for discussions about palliative care at a generalist level. We should also support social care staff to discuss aspects of palliative care sensitively and with confidence.</p> <p>The wishes of the patient are central in determining the answer to these</p>

Question	Response
	questions.
<p>5. What works well in discussing palliative and end of life care and how is good practise communicated? Where do the challenges remain?</p>	<p>Staff need sufficient time and there is often more than one discussion (not just the patient). They need to have a trusting professional relationship with the patient. They also need to be aware of what discussions have already taken place and they need to have sufficient knowledge of the patient and their condition.</p> <p>There are good approaches and recognised models of communication and communication training.</p> <p>There must be good communication between health and social care professionals following discussions</p> <p>Engaging in sensitive conversations with people who have communication difficulties (e.g.cognitive deficits, learning disabilities and speech/language issues) is a challenge and often leaves these individuals disadvantaged.</p> <p>Sometimes there can be a reluctance on behalf of the patient or their family to discuss prognosis</p>
<p>6. What is the role of anticipatory care plans in supporting Palliative Care discussions and how can their uptake be improved?</p>	<p>These are crucial. Staff must have the training in their completion and must have the time to do ACPs. The content should be shared with families if the patient agrees.</p> <p>Summaries of ACPs need to be more readily shared electronically between staff caring for patients. The Key Information Summary is good but is limited by the requirement for GPs to complete</p>
<p>7. How should information about Palliative Care be made available to patients and their family during any</p>	<p>In paper – easy to read</p>

Question	Response
initial discussions and how easily available is this information?	<p>Signposting to good web based resources</p> <p>Phased information tailored to a variety of learning abilities and with alternatives to written word</p> <p>Videos of patients sharing experience particularly useful</p>
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?	<p>Good training is available but there are often difficulties in releasing staff to attend the training</p> <p>Training needs to be contextualised and outcome focused – to ensure that increased knowledge and skills follow through to improvement in competence and practice</p>
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?	<p>Through audits of care and reviews of significant events</p> <p>Right time for individuals and right time for professionals are not always the same – both perspectives need to be measured.</p>
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?	<p>There is a challenge in the sharing of information as there are so many different systems in place for different professional groups.</p> <p>More staff should be able to input to the Key Information Summary and it should be able to accessible to everyone who is caring for the patient.</p> <p>In the last days of life there should be a shared end of life care plan which remains with the patient</p>