

We need to talk about Palliative Care

NHS Ayrshire and Arran

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Palliative Care Clinical Nurse Specialist

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

These are 2 separate questions. I've worked as a specialist in palliative care for 22 years so have an understanding of generalist/specialist palliative care services within hospice, community and hospital settings. For patients with complex needs whether cancer or non cancer access to Specialist Palliative Care Hospital Services is office hours Mon-Fri approx in the district general hospitals in Ayrshire with out of hours access to specialist advice available 24hours a day from the local hospice in Ayr. The hospice again deals with patients and families with complex needs and has an in- patient unit, day services, community support and education remit. For uncomplicated patients who are palliative a Generalist Palliative Care approach is utilised by community, ward, nursing home and social care staff. They would manage patients until they are unable and have access to specialist palliative care advice and services/review if required throughout the patients & families journey. End of life care will occur wherever the patient is. Staff have access to palliative care guidelines www.palliativecareguidelines.scot.nhs.uk to support best practice in EOL care symptom assessment and management and holistic needs. Patients and families don't always need specialist palliative care services at intervals or indefinitely throughout their journey but the key factor here I think is that they have access to specialist services either for advice or clinical review if required.

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?

Access to specialist palliative care advice and clinical review is available in Ayrshire. There is more recognition from generalist staff when patients become palliative but there is scope to widen this approach and insight further through improved education in nursing/medical/ANP, AHP and social care staff. Strengthening links to hospital and hospice specialist palliative care teams and knowledge of when timely referrals to specialist services are in the patients and families best interests would also be helpful. A palliative care register is already used within most GP practices within Ayrshire for patients with an anticipated prognosis of less than 1 year however some lists don't include patients with dementia and other non malignant diseases that could fall into this category.

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

A palliative care approach should be achievable by staff irrespective of care setting rather than when a “palliative” label is used for a patient and some staff/patients/family immediately think this means specialist palliative care/hospice/Macmillan care and is therefore someone else’s role/responsibility. A palliative care approach should cover any disease that is incurable but staff need to be made aware of this and supported in developing these approaches and symptom management.

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 variable as sometimes patients have an incurable illness but are still receiving treatment /interventions sometimes for years. There can sometimes be a reluctance for example by some clinicians to use the term “palliative” due to the perceived distress this may cause for patients and families, they may prefer to use alternatives such as best supportive care or disease control, which although correct may mean the patient/family and carers don’t realise the approach is still palliative alongside their treatments. Ideally a “palliative approach” term should be used at the time when the disease is recognised as incurable. The patient, family, senior clinician and CNS, POA could be involved. Ideally discussion should be initiated by the senior clinician (consultant/GP) when results are available, ideally in privacy whether in hospital/home/clinic/GP practice.

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

Honesty, privacy, compassion, good communication and listening skills. Communication and information should be timeous and patient focussed on their and their family’s needs and wishes, true informed consent re treatment options and realistic effects of hopes of same. Realistic hope and goal setting. Ideally outcome is patient and family focussed /agreed. Should be communicated to relevant healthcare team involved. Use of Key Information Summary (KIS) is ideal for out of hours community access to relevant information which would include components of care/goals and anticipatory care. Challenges are the terminology, timely communication, letters can take weeks/longer to be typed, lack of confidence in clinicians, shift of responsibility.

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

The role of the ACP’s is patient and family focussed for their preferences during their care, normally done when the patient is well in nursing home sectors. For more complex patients involved in specialist palliative care it may also involve treatment withdrawal, escalation/ceiling care etc. Despite a

significant role out in Ayrshire uptake is poor and rare for patients to come into or go out of the acute settings with a formal ACP document. Personally I have only had 2 patients who preferred to use the document instead of the information being included within the Key Information Summary and/or within clinical notes. The patient goals and wishes may be assessed and known by the teams and communicated via other means rather than the ACP document. We have been encouraging discharge letters/summaries/referrals from wards to GP's and DN's to include this information, we also request the GP (and encourage ward medics) to populate/update the Key Information Summary re desired place of care and death, resuscitation status, treatment withdrawal, patient goals, relevant eol anticipatory drugs to improve access to information out of hours which will hopefully reduce patient/family anxiety and be a n informative base to focus a discussion should the patient require Out Of Hours review, may hopefully also reduce number of patients being admitted to hospital in their final days of life unless this is their preference.

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?

Depends on whether it is generalist or specialist palliative care. Clinicians normally would discuss with the patient and family that they want to involve specialist palliative care for a specific reason ie complex symptom management/emotional support/success to hospice services etc. Some wards have a basis information leaflet on what palliative care is (generalist). The hospital specialist palliative care team leave leaflets with patients they review with more detailed information, guidance and details of additional services available. Ayrshire & Arran, Ayrshire hospice websites, the intranet/Athena, the internet also have detailed information on palliative care. For patients in hospital who need specialist palliative care follow up in the community we would refer onto the hospice specialist community nurse, they are also accessible via other health care professionals referrals across healthcare settings within Ayrshire.

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?

The hospital specialist palliative care team, Ayrshire Hospice, Macmillan, dementia courses, eLearning and experiential learning etc are available to access. Trying to enable staff to get time to attend is difficult due to resources and constrains for them even to attend mandatory training

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? These are 2 things – palliative could be years

End of life - can be planned for from anytime of diagnosis through to final hours or days. The right opportunity will be when the disease becomes incurable, at any point the patient wishes to discuss it and when end of life when the treatments are not working or being withdrawn.

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?

Variable as documentation isn't shared. Dictation & letters across services and health boards is variable and therefore untimely. Despite the role out of the ACP formal booklet it is rarely used in acute areas. We liaise directly with the GP's for patients known to the hospital specialist palliative service and request they update the KIS of all relevant information important to and for the patient/family/clinician. This allows access in community by GP/DN/OOH but ideally access should be allowed for any professional involved to see this ie when in emergency departments/hospice clinicians/visiting oncologists etc.

Anne Harvey
Clinical Nurse Specialist in Palliative Care

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

Access is variable. Most hospital teams refer to specialist palliative care at times of complex symptom management or complex family distress, or to facilitate ongoing specialist palliative care in the community. However, many teams within the hospital engage the specialist palliative care team for advice only while self managing both palliative patients and patients at the end of life. Most patients at end of life will be managed by generalist staff with no need to access specialist palliative care services. Specialist palliative care is often involved to facilitate discharge and to support patients achieving end of life place of care choice. The local hospice provides out of hours advice. Complex patients will be referred to the community specialist palliative care team for ongoing support. Those who need generalist palliative care only will be referred to the DN service.

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?

Through person centred approach to care. MDT decision making Encourage staff to access, and utilise referral guidelines. Continued staff training to encourage referral of complex patients regardless of diagnosis. The aim to provide increased knowledge to all staff. Training of ANP staff. Care homes and DN to increase knowledge.

Patients who are deemed palliative should be on a palliative care register in the community as part of the gold standards framework. In Ayrshire and Arran there is access to both hospital and community specialist palliative care services.

End of life care- it should be acknowledged that the patient is now dying and that their care plan should encompass the focus of best supportive care. No matter whether the patient is at home, in a care home hospital or hospice the care delivered should be with the focus of comfort and working towards a

peaceful death. Therefore care givers may be DN nursing home staff or generalist hospital staff. Specialist palliative care team may be involved for more complex patients/those patients who die in a specialist unit ie hospice. Specialist palliative care advice may be sought to support generalist teams without actively being involved. Teaching is aimed at offering patient the access to specialist palliative care as appropriate regardless of diagnosis.

In rural areas access may be through tele-health or satellite clinics.

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

Rural areas and poorer socio economic areas where patients may have difficulty accessing services and also may have the higher care needs. Increasing training and access to online support for patients their families and for staff. Access to 7 day service may be appropriate but would be a resource issue.

Patients at end of life will generally have nurses involved who provide 24 hour service in the community, hospital or care homes with OOH support. However currently in Ayrshire specialist palliative care services are 9-5 Mon-Fri with OOH advice available via the Ayrshire hospice

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?

At the time of identifying life limiting disease. This means people can begin to consider options re anticipatory care planning. This may be in controlled home environment as a patient deteriorates or may be in a more acute care context where it is clear that needs are palliative even at the time of presentation of disease. Initiation should be by the most appropriate person at that time eg GP DN specialist palliative care nurse in the community. A consultant or nurse specialist at out- patient clinic. Ideally in an unhurried environment. In a place where the patient is comfortable enough to engage. This may be with family present, in the patients' own home or a place of care with familiarity. The patients comfort throughout should be the priority. This may involve several ongoing conversations as the patient comes to terms with changing needs. In the acute hospital these conversations will often evolve when meeting the specialist palliative care team and through their ongoing assessment. .

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

What works well: ensuring the patient/family are aware of the situation if they fully understand and acknowledge this then this will aid informed conversation and decision making. Identifying and acknowledging patients needs/choices/desires and working in partnership with them in order to strive to achieve their goals. MDT involvement and discussion so all involved with care have a clear role.

Good practice is communicated: at time of MDT discussion with timely feedback to the patient/family and documented outcome. Through update of teams eg updating GP and the patients key information summary. legible documentation.. ongoing communication/liaison with relevant other professionals as well as with patient and family.

Challenges: receipt of written communication from other care centres is often very slow and therefore inhibits accurate up to date information being shared. Conflict between team members re direction of care. Conflict between family re choices. Collusion between professionals and family members. End of life planning which needs to be tailored to the individual/ however with recent LCP withdrawal this has caused upset in some of the terminology used when planning end of life care.

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

Anticipatory care planning informs discussions re patient choice, thereby having a goal to work towards as well as knowing extent of treatment desired. If staff have access to this information and can discuss with them then it aids their ability to act as patient advocate. It also encourages families to be involved with care planning. It may reduce stress, to both the patient and their loved ones at times of treatment withdrawal if these situations have already been planned for and thought about. This may avoid unnecessary interventions being continued at times of distress. It can inform place of care choice and place of death choice, as directed by patient wish wherever possible. ACP can help inform medical teams/community teams when planning direction of care and desired outcome.

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 should be given sensitively, verbally through either one to one contact or with family member present to support. This may be through discussion with medical staff, nurses, nurse specialists, specialist palliative care team members. This should be in an environment that is quiet and appropriate where possible. In hospital however this may often be in a six bedded room environment. Patients should be given time to process information. Staff member should ensure understanding by questioning patients/family understanding to ensure no doubt re info being shared. There is a lot of written information available, eg Macmillan leaflets and brochures, hospital palliative care leaflets, hospice leaflets. Information should be readily available, in acute setting within ward resource holder. Through contact with specialist team. Or family can be directed to Macmillan website for further info as appropriate. Access is available through various literature and websites in particular relation for dealing with children/young adults.

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?

Through training at the point of induction to new roles there is time allocated for palliative care. online courses via learn-pro around palliative care and bereavement. Through Athena hospice education can be resourced. Staff are encouraged to access those courses relevant to their area of practice. Specialist staff teach informally in their care environments on a daily basis and encourage staff to sit in on consultation for experiential learning. Locally Paisley UWS have enjoyed a Macmillan funded project to upskill senior staff in palliative care issues which offers a full week of experiential learning across hospice, day services inpatient unit services and community services, as well as time spent with acute hospital palliative care team. Their roles are to share their learned knowledge and promote confidence with care of both palliative patients and those at the end of life within generalist settings. Improvement could be made if staff were allocated more time for ongoing training but this access to training is difficult over most areas due to limited resource/time.

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?

This should be achieved through ongoing evaluation of patients. By ensuring that patients are tapped into all appropriate services and therefore are closely monitored. Through monitoring then staff/family should recognise time of decline in health. Through this anticipatory care can be discussed and implemented accordingly.

End of life care is a separate issue from palliative care, therefore a diagnosis of dying should be made before end of life discussion takes place.

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?

Challenges: at times palliative specialist advice is sought at a time where there has been no discussion to inform how far care should be escalated if the patient becomes more unwell, the palliative care priorities would be about symptom management and managing and reducing stress to the patient/carers/family. Therefore this means directly accessing staff caring for the patient and clearly trying to identify their goals/aims of care. At times it would be appropriate to be providing specialist palliative care while a team is actively managing a patient's disease. However, at others a purely palliative approach is desirable. The communication of priorities will be face to face discussion, written within medical notes where information is shared. Through telephone calls to eg community staff ie GP D N updating KIS (key information summary) information hospice teams MDT members SW Some info will be shared through letter writing, however not all services letters are produced timeously.

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