

We need to talk about Palliative Care

North Ayrshire Health and Social Care Partnership

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

Generally access to specialist Palliative and End of Life Care has been limited for those living in the community and as a result some people have died in hospital or other inpatient settings.

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 the development of high quality, locally delivered end of life care. This can be achieved by working with the Ayrshire Hospice and other partners to design and deliver end of life care that builds capacity within local health and social care professionals while ensuring rapid access to specialist advice and support from the Hospice to support individuals across North Ayrshire Health and Social Care Partnership area to design and fulfil their end of life care plan. A key element of this will be building specialist capacity in our Care at Home, District Nurse and GP teams to support individuals and their families in the community and to develop specialist inpatient facilities outwith our community hospitals.

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

I think the development of palliative and end of life care in people's own homes should be focussed on as a priority. Also palliative care services for people with dementia require further development. In addition to this, the development of family liaison roles to co-ordinate care and support should be a key development.

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?

Open, honest and transparent conversations should take place. The professional who knows the person best or who is most involved in their care should ideally be involved in determining when the initial conversation regarding options for palliative care should take place and then in leading the communication itself.

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

Being able to offer a range of options for palliative and end of life care works well. It is important to recognise that diagnosing dying can be

complex and therefore the views of a Multi Disciplinary Team should be taken. The challenge of de-stigmatising death, dying and bereavement still exists and work is required to address this.

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

Anticipatory Care Plans (ACP) play an important role in the delivery of palliative and end of life care. The completion of ACPs need to be encouraged early in the person's health and care journey and should not be left until the palliative and end of life care stage.

ACPs should include all the information that will ensure the individual can be cared for with dignity and respect until the end of their life. Physical, psychological, social and spiritual needs and wishes should be included in the ACP, The person's preferred place of care should be identified and achieved if possible.

That said, ACPs are only effective if they are assessed and utilised by wider clinical and care teams. Clear Guidance and Standards for this are required to ensure it is incorporated into practice.

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?

Open, honest and transparent conversations should take place. The professional who knows the person best or who is most involved in their care should ideally be involved in this initial conversation regarding options for palliative care.

Information should be available in a range of formats – leaflets, web-based and telephone support to enable engagement on reflection.

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?

More Education and Training is required. On line resources have significantly improved and uptake should be encouraged. Good practice should be identified and shared.

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?

The right time has to be, when the patient and the family are ready. The Multi-Disciplinary Team should recognise the right time to be having the "Palliative Care Conversation" and the professional who knows the person best should initiate the conversation.

Consultation and the use of Carer Satisfactory Questionnaires can be used with families following the person's death to gather information on how timely and appropriate conversations were.

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?

We should develop a single access point between the organisations involved as this may help with some of the current barriers for example IT systems that don't allow information to be shared between agencies / organisations.

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