

We need to talk about Palliative Care

Aberdeenshire Health & Social Care Partnership

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

Within Aberdeenshire we have had both positive and challenging experiences.

We have been very fortunate in having 24 hour access to helpful palliative care advice from Roxburgh House (specialist palliative care unit in Aberdeen); this has been universally praised.

We have delivered an increased use of 'Just In Case Boxes' in the community and this has been very successful from all points of view.

The most commonly cited challenge by all practitioners is the lack of carers to support people who wish to remain at home for end of life care. The current system falls short against our desired approach in terms of the number and availability of carers, the amount of time they are able to spend with a patient and the speed at which care management can respond.

In Aberdeenshire community hospitals beds are an important part of being able to care for patients who require medical or nursing inpatient care, as close to home as possible. Our community hospitals, with the nursing and medical input have the potential for close to equivalent hospice care. Recent pressures on community beds (increasing demand & delayed discharges) can impact on the availability of community hospital beds for high quality palliative care being delivered close to people's homes.

The shortage of out of hours nursing has been an issue, both in terms of out of hours community nursing cover (gap at start and end of working day), and planned Marie Curie care e.g. sometimes patient admitted as unable to guarantee that Marie Curie overnight nurse will be available.

2. How could it be ensured that access to palliative care and end of life care is equitable and available in all areas and for all types of terminal illness?

We have a general feeling that we are still better at identifying terminal illness in patients with cancer than other types of illness, and in providing care for them. Palliative care DES returns have suggested that practices are becoming more confident about using SPICT to identify patients with palliative care needs but sometimes find it harder to decide to put a patient with heart failure/COPD on palliative care register as although they might die within next 12 months, they might also live for much longer. Some practices have "supportive" or "pre palliative" register.

There can be a wide variation in care homes and how they cope with patients needing end of life care. Although a lot of good work has gone on in recent years in training staff in care homes on the Grampian Integrated

care Plan, the higher turnover of staff can make it difficult to maintain knowledge, so a rolling training programme is important.

Access to out of hours care, both medical and nursing needs to be locally based and to be able to respond to patients timeously, despite the difficulty of rural locations. There is a difference between the way care is delivered in Aberdeenshire and Moray, as opposed to Aberdeen City and there is general concern in primary care re the inequity of access/ possible delays in response times because of this.

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

As above and below the, overwhelming priorities are carers and community nursing (both in and out of hours).

4. When is right time to begin discussions for Palliative Care, who should be party to that discussion, who should initiate it and where should it take place?

The right time depends on the individual patient. It should be with someone who knows the patient and their case. The patient should be asked who they want to be involved in discussions about their care. Whether it is specialist Dr or nurse, GP or community nurse is less important than someone having sufficient uninterrupted time to sit and discuss it somewhere suitable.

Increased earlier recognition by secondary care that further intensive treatment may be futile and communicating that to patient and family in a way that is supportive.

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

Continuity of care is important so that patients are looked after by medical and nursing staff who know them. Palliative care DES returns showed that increasing GP demand is impacting on GPs ability to provide as good palliative care as they wished to. Despite wanting to go the extra mile in such situations it was becoming more common that practices were having to respond to palliative care patients on a crisis basis, rather than having enough time to have these discussions, make plans and review them.

Provision of palliative care at home depends on high quality community nursing and the ability of the team to cope with significant additional workload, often compounded by the rurality of Aberdeenshire.

Regular Palliative Care SEAs within primary care teams helps to raise awareness of issues, as well as reinforcing good practice, and providing support after difficult cases.

There can be a perception that palliative care is a specialist area, especially when secondary care feel a patient is at a terminal stage of their illness. Whilst a small number of patients with complex palliative care needs require

referral for specialist care, most patients need generalist palliative care. This can best be delivered close to home by an adequately resourced health and care team who know the patient and their family.

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

KIS has made this much easier however not always used in care homes / community hospitals as perception that staff will be able to give information, but can be useful if bank/agency staff.

It would be useful if secondary care were able to update it from their end but not possible with current IT systems. SAS do not always seem to access them if 999 call.

7. How should information about Palliative care be made available to patients and their families during any initial discussions and how easily available is this information?

Macmillan has a lot of useful resources available. Maggie's and CLAN, as well as Macmillan nurses, all provide good support to patients.

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?

Excellent local training for health and care staff provided by Roxburgh House with widespread coverage e.g. 14993 people have been spoken to re Palliative care education, including over 500 attending for education on dementia (includes carers).

Care home staff being able to access NHSG clinical intranet guidance on Palliative Care would be valuable.

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?

Recognise that providing good quality palliative care is time consuming- medical, nursing and care staff need to be adequately resourced and have the flexibility to be able to respond to patient and family's needs.

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?

The big issue is the different IT systems used in primary, secondary and social care. Recent survey of use of KIS in secondary care found that hospital staff were more likely to look at KIS in unscheduled care and if person had comorbidities and was very ill. However they struggled to find it in hospital IT system, but if they did they almost always found it useful. 93% commented would like to be able to access "read only" view of GP records and 61% would like to be able to access social work records.

Another issue is that KIS/ epcs needs to be kept up to date and reviewed on regular basis.

There can be communication issues between secondary and primary care e.g. DNACPR discussed but form not sent home with patient (would be useful to be able to use IT to alert all professionals, including SAS, that patient had DNACPR, without needing paper copy to be with patient). Unrealistic expectations given to patient and family of what care is available in the community.

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