

We need to talk about Palliative Care

Strathcarron Hospice

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

Access issues can be categorised as capacity; awareness or geographical issues

In terms of access, the capacity of specialist palliative care services is limited and therefore rationed. Strathcarron Hospice regularly has a waiting list for admission and our community palliative care services have huge workload pressures. There is no hospital palliative care available at weekends.

In terms of awareness, a better understanding of the range and scope of palliative care provision would improve access. Referrals rates from other specialties are variable. The Hospice offers a 24/7 telephone advice service for specialist palliative care but this is under utilised

Geographically the distribution of specialist palliative care units is uneven across Scotland.

Some care homes provide very good end of life care and other do not – education is an important factor

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 illness?

Our own service has experienced an increase in non- malignant referrals – from 6% to 26% over the past 5 years.

It is vital that palliative care is maintained as a specialty in its own right. Palliative care training should also be integrated into undergraduate curricula for medicine, nursing, AHPs and social work. Within doctors' training for all specialties, there should be sufficient emphasis given to providing palliative care.

We need more resource and specialist input to support particular types of illness e.g. dementia.

Upskill staff in other specialties in palliative care, supported by education/ specialist units and upskill health and social care staff who care for people in their usual place of residence

Education (e.g. QELCA) training should be provided by specialist services to staff in health, social care and care homes – combining practice based learning and reflection to help change attitudes and practice. Increase funding to Hospices to provide education and mentorship.

Not all primary care staff are aware that they can refer non- malignant patients to hospices.

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

Develop Hospice at Home services to support people in their own homes at end of life and to provide rapid response to prevent admissions.

Areas of access that should be focused on include: cardiac; renal; respiratory; neurological and dementia services. People with a learning disability may also require end of life care,

Educate non- specialist staff in NHS and care homes

Communication between IT systems is negligible.

Engage with minority groups who have low uptake of services.

More research is needed to identify the best interventions and service delivery models for non- cancer patients

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?

There is no “right time”, this depends on the individual and the team around them

The team needs to have an awareness about the importance of initiating palliative care conversations and it should be explicitly communicated and discussed, otherwise people will assume someone else is doing it.

Triggers for discussion include clinical indicators of advanced disease e.g. as summarised within SPICT or for patients in long term care or if initiated by the patient or family.

The discussion should include anyone the patient wishes to have present and should take place with someone who has sufficient knowledge of the patient and appropriate communication skills.

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

Staff need appropriate training in how to talk to patients. They need sufficient time and there is often more than one discussion. 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.

There are good approaches and recognised models of communication and communication training.

Many generalist staff will avoid difficult conversations and assume it is someone else's role

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

Anticipatory care plans or advance care plans? There are huge problems around terminology and whether this is a patient led process or something professionals "do". We need to address medical, legal and personal aspects of care and decision making.

Don't allow uptake to become a "tick box" issue.

There needs to be a better system of sharing information e.g. KIS should be accessed and updated by more than just GPs.

Some patients do not want to engage in this at all and this must be respected. A public health approach to death and dying would impact on public attitudes and people may then be more willing to engage.

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?

There is no answer to this because of the diversity of patients, diagnoses and time scales.

It would be more appropriate to listen to patients' views on this.

We must ensure patients are central to the process of communication and are empowered to share decisions with other members of the team.

8. What training and support is provided to health and care staff on discussing palliative care with patients and families and are there areas for improvement?

Bespoke training could be developed for particular specialties and groups of professionals, subject to funding. Communication skills courses across the whole spectrum of staff are required. There are also opportunities for joint working across specialties.

Improve training/education support for care homes.

All training needs to be ongoing due to staff turnover.

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 Gold Standards Framework in primary care supports the identification and discussion of appropriate patients.

We don't ensure this – how can “the right time” be defined? Some staff will avoid these conversations and too often the palliative care professional is left to have a conversation that should have happened earlier

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?

Sharing data through IT systems is challenging but needs to improve.

Clinical situations change rapidly so the documenting system needs to be responsive to this.

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