

We need to talk about Palliative Care

Association for Palliative Medicine

The Association for Palliative Medicine of Great Britain and Ireland (APM) is an organisation of over 1,000 palliative medicine doctors and medical students working or interested in adult palliative care in hospices, hospitals and the community. We welcome the Scottish Parliament's Health and Sport Committee inquiry into palliative care and have answered the 10 questions below:

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

Palliative Medicine has been recognised as a medical specialty in the UK since 1987. Our members have a wealth of experience of working with patients with supportive and palliative care needs across all settings – community, hospital and hospice– to provide specialist support to patients with any advanced illness.

Specialist palliative care advice is available by telephone to community and hospital teams providing out of hours care across Scotland. This service is usually provided by consultants and is therefore more challenging to sustain in areas where the consultant is single-handed.

Face-to face specialist palliative care assessment is not available seven days a week in most areas of Scotland as there are too few specialist staff available to resource such a 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?

All clinical teams in both hospitals and community should be supported to acquire and maintain skills and competence in providing good quality palliative care for patients and their families, including familiarity with and access to the Scottish Palliative Care guidelines.¹

There needs to be equity of access to specialist palliative care in all settings (community, hospital and hospice), so there can be a timely response to patient needs 24 hours a day and 7 days a week, including early referral, help in managing distressing symptoms and psychosocial distress, enabling generalist staff to access support to assess whether or not patients are nearing the end of life. Such access to specialist advice and support would depend on easy and immediate access to electronic records which are fit for purpose and should be supported by models of care that provide access to palliative care nurse specialist assessment 7 days a week. Service referral criteria should not be restricted on the basis of diagnosis but should be on the basis of need in the context of a life limiting condition.

It is important to resource adequate specialist palliative care services in hospitals as well as in the community because many patients with non-cancer illnesses are first identified as having supportive and palliative care needs during a hospital admission and most people have at least one acute hospital admission in their last year of life.

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

Our key recommendations to improve supportive and palliative care are:

- a. Ensure specialist palliative care clinicians are resourced to provide appropriate leadership input to the Integrated Joint Boards for Health and Social Care to end the separation of health and social care funding for patients nearing the end of life. Appropriate focus and prioritisation of scarce resource must make it simpler to access and coordinate rapid, and responsive care which addresses and supports the goals of care of patients and families. Prompt and individualised social care must be available for patients who wish to be discharged home from hospital, stay at home and die at home.
- b. Ensure that generalists who care for patients in their last days of life receive mandatory and on-going training and education in core palliative skills and knowledge to ensure good end of life care in all settings.
- c. Ensure equity of access to specialist palliative care in all settings as discussed above in point 2.
- d. Integrate specialist palliative care teams across boundaries to provide seamless care for patients.
- e. Specialist palliative care teams to establish good patient pathways to make sure those patients requiring interventions e.g. radiotherapy or nerve blocks can get rapid access to treatments.
- f. Stakeholders and research funding bodies to prioritise supportive and palliative care research to ensure we learn for the future, as stressed in the Neuberger review.
- g. Ensure that robust data is collected nationally and made available at a local level for service development and redesign, quality assurance and performance management. Data should be less focused on activity and process and more focused on outcome measures which are truly patient-centred and reflect patient and family experience. Development of national quality indicators and standards (such as the National Care Standards) provide an opportunity to improve the relevance and applicability of national palliative care scrutiny. Specialist palliative care clinicians must be adequately resourced to provide appropriate and truly representative input to the development of such standards.

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?

Palliative care should be discussed whenever and wherever a need is identified – be it physical, psychological, social or spiritual. This can be early on in a patient’s illness as good palliative care can, and often should, run concurrently with disease-modifying treatment. Identification of patients who are deteriorating, or whose health is at risk of deteriorating, is essential if timely discussions are to be offered. The patient and anyone significant to them should be involved in the discussion, as well as a healthcare professional. Any healthcare professional should be able to initiate such a discussion when a need is identified – initiating the discussion does not necessarily mean that person has to be able to meet those needs; rather that they open the option of palliative care to the patient and then direct them as to where their need may be best met. Organisations have a responsibility to ensure that appropriate environments for sensitive discussions are readily available in all healthcare settings.

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

Sensitivity to and respect for different coping strategies is important as some people will want very detailed information to allow them to plan ahead while others will find this approach too distressing. It should be possible for staff to engage in a sufficiently individualised way that patients are enabled to plan “just in case” while retaining hope for improvement. The person leading the discussion should be able to communicate that palliative care is not synonymous with end of life care and neither does it preclude ongoing disease-modifying treatment; rather that it is about addressing symptoms and optimizing quality of life in the context of a potentially life-limiting condition. They should be aware of what local services are available to patients, which may include specialist palliative care services. It is important to ensure patients and families are aware that much good quality palliative care is delivered e.g. by the patient’s own GP and district nursing team. Challenges remain in ensuring that discussions are had in an informed and sensitive way due to a variety of inhibiting factors such as lack of time; lack of access to appropriate privacy; lack of staff confidence and competence in engaging with patients and families in this way; and lack of staff and public awareness about the positive role of such discussions and their potential for improving the quality and person-centeredness of care.

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

Anticipatory care plans are of great value. They should contain information to allow appropriate care to be provided in emergency situations as well as information to support management of specific anticipated symptoms and clinical situations to reflect the patient’s agreed goals of care e.g. a patient who is prone to significant breathlessness but not keen to be admitted to

hospital can develop an anticipatory care plan about managing breathlessness at home. Their uptake can be improved by ensuring that healthcare professionals know that it can be anyone who completes these with the patient and does not have to be deferred to a specialist team. Scotland is fortunate in having a national electronic ACP record (the Key Information Summary – KIS) which is widely accessible. Efforts must be made to improved awareness of this tool and its potential to inform goals of care discussion and support high quality palliative care. Resource to improve the format, content and accessibility of the KIS should be a priority for all Boards and hospital admission and discharge processes need to connect effectively with the KIS so that relevant ACP information can be transferred immediately and acted on.

Staff training in the use of existing ACP tools such as the KIS and in the communication skills necessary to support ACP discussions must be prioritised. Boards should be encouraged to promote the existing online training modules for example the advance and anticipatory care planning toolkit on the palliative care in practice portal of the knowledge network.²

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?

Most palliative care services have written and online information available to professionals, patients and families, but work needs to be done locally to ensure that other professionals know of its whereabouts.

Palliative care organisations should continue to work with charities and patient groups to develop patient and carer information that promotes an awareness that palliative care is not just about death and dying but is about living as well as possible with any life-limiting illness; many charities already have such materials.

Boards should ensure that information about generalist palliative care is integrated in any patient material which relates to the local services supporting the management of long-term conditions.

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?

As discussed above in point (3) it should be ensured that generalists who care for patients with life limiting illnesses receive mandatory and on-going training and education in core palliative skills and knowledge. This is essential to ensure good supportive and palliative care in all settings. Supporting staff to feel confident in initiating discussions around goals of care and future planning is essential in all acute and community settings including (and very importantly) in care homes. There is a great need for additional resource and service redesign focus to allow this to happen. Time must be provided for staff to engage fully with existing online resources and to attend study days and reflective sessions. Champions for

palliative care skills and values should be trained and supported in every setting to promote and sustain a quality improvement approach to ensuring high quality palliative care.

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?

Organisations need to be responsible for developing their own systems to make sure that these discussions are occurring and at the right time. It comes back again to education for all those involved in delivering palliative and end of life care and support for a quality improvement model which promotes sustainable local improvement projects.

Organisations also need to develop systems for assessing local patient and family need and experience in a way that can be used to immediately inform service redesign and development. Organisations have a responsibility to improve access to, and awareness of, the relevant patient and family participatory research that has highlighted national service gaps and to inform and support future work in this area.

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?

Improved use of the existing KIS electronic system is essential and this resource should be improved and expanded to support the consistent communication of relevant goals of care and palliative care priorities across all healthcare settings. The responsibility for supporting GPs to improve the information available via the KIS lies with all healthcare professionals and not just with specialist palliative care teams and it is essential that Boards find ways to ensure this is prioritized and as easy to do as possible.

Many specialist palliative care services are not integrated across boundaries and are discrete teams for hospitals, hospices and in the community. Such teams need to find ways to support the sharing of information about patients to provide seamless care for them.

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References

1. <http://www.palliativecareguidelines.scot.nhs.uk/>
2. <http://www.palliativecareinpractice.nes.scot.nhs.uk/advance-anticipatory-care-planning-toolkit/introduction.aspx>