

## We need to talk about Palliative Care

### Royal College of General Practitioners (RCGP)

The Royal College of General Practitioners (RCGP) is the academic organisation in the UK for general practitioners. Its aim is to encourage and maintain the highest standards of general medical practice and act as the 'voice' of general practitioners on education, training and issues around standards of care for patients.

The College in Scotland came into existence in 1953 (one year after the UK College), when a Scottish Council was created to take forward the College's interests within the Scottish Health Service. We currently represent over 5100 GP members and Associates in Training throughout Scotland. In addition to a base in Edinburgh, the College in Scotland is represented through five regional faculty offices in Edinburgh, Aberdeen, Inverness, Dundee and Glasgow.

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

To establish the issues for access requires clarity in the definition of palliative and end of life care. The General Medical Council, in its publication *Treatment and Care towards the End of Life*, states that 'patients are approaching the end of life when they are likely to die within the next 12 months'. The definition of end of life care is therefore not restricted to care in the final hours or days of life but is increasingly used to include the months and even years before death.

As stated in the current RCGP Scotland Policy Document on End of Life Care, the provision of end of life care is a core component of the work of a general practitioner. Although the majority of deaths still occur in NHS hospitals, 90% of a patient's last six months of life are spent at home or in a community setting. Primary care teams, in which District nurses play a key part, have a central role in coordinating and delivering the care that these patients require and contribute very considerably to end of life care.

Our Policy document outlines the issues facing primary care teams. GPs provide care, on a daily basis, for patients with a range of incurable conditions but the transition to the 'end of life' phase may be difficult to appreciate. Identification tools such as the Supportive and Palliative Care Indicator Tool (SPICT) or the GSF Clinical Prognostic Indicator support the identification of patients irrespective of the underlying disease or illness

The current workload pressures facing general practice have been well publicised in the RCGP ['Put Patients First: Back General Practice'](#) Campaign and in the recently published [A Blueprint for Scottish General Practice](#) document. These highlights the potential challenges in providing the level of access required to meet all the needs of our palliative patients and their carers. Never the less, our policy document reports the results of the 2012 membership survey which identified Palliative and end of life care as one of

the top three clinical priorities for GPs and provides evidence of the ongoing commitment of practices to prioritise stretched resources into ensuring access and appropriate care for these patients.

Delivering end of life care is a core component of general practice care which also relies on the additional support of social services and third sector to support care at home. Experiences of practitioners across Scotland would suggest the level of access to this support can be variable with significant resource issues within local authorities. Specialist Palliative Care services are generally an excellent source of decision support, expertise and inpatient palliation when required but immediacy of access can also be variable.

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?

Inequities in available resources are referred to above and include the different capacity issues and pressures on GP practices across the country, the difficulties in socially deprived areas and the geographical challenges for remote and rural and apply to all areas of health care. There is a recognised issue in identifying the time of onset of palliation and when care becomes end of life in terms of patient recognition, acceptance and agreement of the defined goals for care and support. Much of what is required at this stage is time spent with patients building relationships rather than specific interventions and it is a real challenge offering sufficient time when there is very limited capacity to do so. To encourage equitable access for all types of terminal illness there is still a need to continue to raise general awareness amongst patients and their carers that palliative care and end of life care is not only about cancer and that this care applies to all types of terminal illness and should be accessed.

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

As above, the need for investment to sustain general practice and to provide the social services infrastructure required to support care at home have to be the key priorities.

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?

Timely discussion is a judgement which presupposes the definition of palliation and assessment of patient readiness. Any discussion around care – what can and should be offered, outcome limitations and expectations, genuine and realistic choices – can be had with anyone involved with the patient's care as long as they are trusted by the recipient. GPs and District Nurses are key figures in the community team. Guidelines on communication dictate a safe and appropriately supportive environment free from interruptions or distractions.

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

As reported in the RCGP Scotland policy document, historically, there has been reluctance within society to discuss the subject of death and dying and to acknowledge that these are inevitable consequences of life. A Scottish Partnership for Palliative Care [SPPC] report [Public Awareness of Palliative Care](#) from 2003 indicated that 70% of people in Scotland thought that as a society we do not discuss death and dying enough.

The strategy for communication with patients in the RCGP Scotland policy document states that it must be compassionate and allow involvement of the patient and family in decision making. It should include a willingness to have open discussions of end of life issues

Sharing good practice between different primary care teams is the aspiration but is faced with the challenge of time and capacity to do this. A future vision for GP clusters within the locality structures of the IJBs offers an opportunity to facilitate this provided there is sufficient investment to support this activity.

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

Anticipatory care plans encourage patient and family involvement and provide a useful form of communication between the caring agencies and in particular, between day time and OOH care. Wider agency involvement and better integrated IT would enhance the benefits of ACPs and perhaps generate greater uptake but their limitations must also be considered in the context of each patient.

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?

GPs would aim to apply skilled communication with appropriate sensitivity and sharing of relevant patient information resources at a time judged to be most appropriate for the patient and their family

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?

Training resources are readily available to GPs but time for meaningful and shared multi-professional learning events remains a challenge within the constraints of the current climate described above

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?

As above

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?

These should form part of good anticipatory care planning and ePCS. The key challenges are the current IT systems and a lack of a unified system across the different agencies.

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