

GPs' vital role in end of life care

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THE AIMS OF PALLIATIVE CARE ARE TO PROVIDE THE BEST QUALITY OF LIFE FOR PATIENTS AND THEIR families, and to facilitate a good death. The NICE quality standard on end of life care, published in November 2011, consists of 16 quality statements (Q1-Q16) which inform patients of the standard of care which they should expect and define aspirational standards for clinical governance.¹

If patients are to die well, they need to be prepared for death, to achieve a sense of control, to be free of pain, to be respected as an individual, and to spend meaningful time with close family and friends in familiar surroundings.^{2,3}

Only 1 in 4 deaths are caused by cancer,³ and it is now recognised that high quality palliative care should be extended to other patients.⁴ There is much room for improvement. Most patients with end stage organ failure have not had an end of life discussion with their doctors.^{5,6} Fewer than 1 in 5 patients (9–20%) cared for by specialist palliative care services have conditions other than cancer.⁷ There is compelling evidence of inadequate end of life care for dementia patients.⁸ And fewer than 1 in 5 patients die at home.³

GPs have a key role in identifying patients who are likely to die within the next 12 months (Q1). We should offer to discuss what to expect, in a sensitive way, and communicate information clearly and honestly (Q2). In practice, it can be very difficult to judge the right time at which to initiate a discussion. The disease course may be unpredictable and prognostic indicators can be unreliable. A recent Scottish study found that only 1 in 3 patients identified by the Gold Standards Framework prognostic indicators for heart failure died within 12 months.⁹ It is also hard to gauge when patients wish to talk: often doctors and patients wait for one another to start a conversation, both fearing to take the first step.⁵

We should ensure that patients approaching the end of life are offered a comprehensive assessment and given the opportunity to participate in advance care planning (Q3). Advance care planning enables patients' wishes to be known and respected at the end of life, enhances family satisfaction and reduces the risk of depression in surviving relatives.¹⁰

We should provide effective symptom control (Q4), emotional, social and spiritual support (Q5–6), and co-ordinated care (Q8). A palliative care handover form can facilitate communication with out-of-hours services.

Many carers are older people with their own health

problems, home care of the dying can place considerable burdens on the family, and more than one third of carers experience psychological distress.¹¹ GPs have neither the time nor expertise to carry out a comprehensive carer assessment (Q7), but we should recognise carers, perform a brief assessment of their needs and refer when appropriate. There is evidence to support use of the screening question: 'Overall how burdened do you feel?'¹²

We need to make a timely diagnosis of dying and provide co-ordinated care in accordance with the patient's personalised care plan (Q11). Use of the Liverpool Care Pathway is recommended.

End of life care does not stop at the point of death.

GPs have a key role in offering appropriate bereavement support to those closely affected by a death (Q14). This should be done in a structured way e.g. through a practice bereavement protocol¹³ and should incorporate a risk assessment. The surviving spouse/partner should be contacted as soon as possible: suicide rates in the first week after bereavement are 20–30 times the expected rate, although the absolute risk is low.¹⁴

We need to be careful to avoid overdiagnosis of patients approaching the end of life, thereby causing unnecessary worry, loss of hope and the swamping of palliative care services. At the same time, we can make a huge difference to the experiences of patients and their families through timely recognition of end stage illness and provision of high quality care in accordance with the new standards.

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