

# Learning from death

Over the past century, death has retreated from our homes. In DH Lawrence's *Sons and Lovers* the description of William's 'bright brown ponderous coffin' resting on chairs in the Morel's small parlour now seems an image from a very distant past. Death has also retreated from many of our lives. Like others, I have reached my fifth decade without having been significantly bereaved. The increasingly frequent and generally violent portrayal of death in the media serves to mislead rather than to inform us about how we can expect to die. As a consequence, the majority of people in the United Kingdom today do not actually know what the process of dying is like.

In the first half of the 20th century, most deaths in the UK took place in people's homes. By the 1960s this had dropped to one-third and the decline continued right up into the 1990s. The latest figures for cancer deaths show a halt, and possibly a slight reversal in this trend (25.5% in 1992, increasing to 26.5% in 1994).<sup>1</sup> There are complex reasons for these dramatic changes, such as changing family structure, social mobility, secularisation, and an ageing population. As a result of this flight from home, people have become de-skilled in caring for the dying outside institutional settings.

General practitioners (GPs) and district nurses now occupy a special position in society. We do know about the process of dying, both in hospital and at home. We have seen good deaths and we have seen bad deaths and many of us have thought deeply about what distinguishes one from another. Only home care specialist nurses and some ministers of religion share this privileged position.

Carers who have nursed patients at home will have a specific body of knowledge, but usually lack a breadth of experience. It is this breadth of experience that teaches us about the importance of openness, good symptom control, and supportive social networks. It also teaches us that there is no absolute right or wrong way to die and that, in the end, each patient and their family must find their own way. I was certainly shocked the first time I saw a classic deathbed scene played out with the television on in the room, or with the dying patient's last cigarette still smouldering in his ashtray.

GPs learn quite early in their careers that providing good medical care for the dying is a challenging area of their work. It is one thing to recognise the importance of good symptom control, but quite another to achieve it consistently in the absence of 24-hour nursing care. A body of research consistently shows that symptom control, psychological support, and care of the carers is better in specialist palliative care settings than at home or in hospital.<sup>2-6</sup> This has been useful in raising acceptable standards of care, both at home and in hospital. However, the criticism implicit in much of this research also contributed to tensions developing between the relatively new specialty of palliative medicine and general practice. At one time, there was an expressed anxiety among GPs that the development of the specialty would have the undesirable effect of de-skilling the

generalists.<sup>7</sup> Now that palliative medicine is firmly established as a medical specialty, clearly positioned within the secondary services, these tensions are resolving. The relationship between the disciplines is now clear, comfortable, and finally working in the best interests of patients.

As well as establishing good symptom control, GPs have other, less obvious, and certainly less well researched roles. The first is a willingness to talk about the process of dying. We can share the wisdom that we have gained from attending other deaths with our patients and their families. For many, this will be the first time they have given these issues serious consideration. We can encourage them to think and talk about how they would like to die and how, together, we plan to conduct their dying to make it conform as closely as possible to their wishes. We should talk to carers about what will happen after the death. They may need to know what to expect at the moment of death itself and how to care for the body afterwards. They may want to think about keeping the body of their loved one at home for a while before they call the funeral directors. Of course this may be the last thing they want. But if they have had the discussion at least they will have the choice. As with birth, paying attention to these small details can make a big difference to the way people subsequently feel about a death. GPs and district nurses are in an ideal position to help their patients develop an intellectual framework through which to approach the process of dying with more confidence.

General practitioners describe another very important role simply as 'being there'.<sup>8</sup> There is both a physical and a metaphysical component to this. As death draws close we visit frequently, even though there is no specific task for us to perform or problem to solve. Together with the district nurses we shepherd our patients through this intensely emotional and often frightening time. Simply by being there, we acknowledge the gravitas of the events taking place.

'Being there' is also about bearing witness, which has become an increasingly important role for GPs in this secular society. Among other things this teaches us about suffering, about courage, about the love we see within families and between friends. As well as being difficult it is often a very intense experience for the doctor and many find that as a result they feel enriched, both personally and professionally.<sup>7</sup> As one GP said to me recently, 'Every time a patient that I am looking after dies it is both a relief and a sadness to me'.

Because we look after a practice population as well as its individuals, we also have the opportunity to look at why our patients are dying. Over half of all practices keep a record of deaths in one form or another and these provide another way in which we can learn from death.<sup>9</sup> In this issue of the *BJGP* a paper by Webb and Esmail<sup>10</sup> describes how mortality analysis can provide useful insights that may tell us more than we can learn from a simple death register. They demonstrate that, in their inner-city practice, there are nearly four times as many Years of Life Lost associated with a history of

alcoholism and three times as many associated with drug dependency, compared with a control practice. The excess mortality associated with substance misuse is already well recognised<sup>11</sup> and these findings have face validity, even though the small numbers involved lead the authors to question how useful such data are when collected at this level. The difficulty of drawing practice-specific conclusions about death rate from death registers has also been raised in recent debate with regard to the Harold Shipman case.<sup>12-14</sup>

What the death register certainly does is focus our attention on important matters of daily practice. It is highly relevant that an individual practice appreciates the increased mortality among their patients with alcohol and drug related problems. The information may or may not alter policy, but it will almost certainly alter GPs' approach to individual patients. Listed in my death register in the past 12 months are the names and details of five women aged under 65 years — two dead from heart attacks and three from lung cancer. It makes sobering reading and concentrates my mind on the value of preventive work in coronary heart disease and smoking cessation more effectively than anything else that I can think of.

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