

...And in the end, no more pain?

PALLIATIVE CARE For many, the end of life is a taboo subject. Mention palliative care and most of us immediately think 'hospice'. **Lorrie Kelly** explores the current state of care for the dying and how it might be improved



Death is inevitable and yet we live in a society which, for the most part, prefers not to think about dying. Paradoxically, charity donations to UK hospices and palliative-care units can exceed £300 million a year.

For Michael Bennett, Professor of Palliative Medicine at Lancaster University's International Observatory on End of Life Care and chairman of the British Pain Society's Cancer Pain Committee, concern for the dying is a day-to-day occupation.

"Palliative care teams are better at initiating discussions with patients about planning ahead and whether or not to continue treatment. I think that is what distinguishes us," he says. "We offer good basic clinical care, medical and nursing assessments. We ask the patient about their mood, distress and how their families or carers are coping."

But how do we make our death or the death of a loved-one as comfortable as possible and in a place of our own choosing? In essence, that is what palliative care is meant to answer.

According to Professor Bennett, one of the greatest benefits of palliative care is its ability to empower patients. They are more likely to have discussions around resuscitation or withdrawing from chemotherapy treatments, for example. Palliative care gives patients the support and information they need to make difficult decisions.

"The simple act of helping people to prepare for death, helping them choose and plan ahead, actually has a beneficial effect," he says.

Modern hospice care has changed little in ideology since its creation in the 1960s. Jon Andrewes, chief executive of St Margaret's Hospice in Somerset, believes the tried-and-tested philosophy remains true. St Margaret's approach to palliative care

is from the perspective that dying is a natural part of living, he says.

"The hospice formula of care is not just medical," says Mr Andrewes. "It also includes social care as well as warmth and understanding, balanced with honesty. In palliative care we work from the standpoint that someone has a life-limiting illness and the curing process has ended.

"Making every day count is really at the centre of hospice care," he says. "We find that the approach brings patients a sense of wellbeing through knowing where they are and what is happening. From this place, patients achieve a better quality of life."

DIE AT HOME

According to the National Council for Palliative Care (NCPC), 56 per cent of people in England would choose to die at home but only 20 per cent actually achieve this. In reality, more than half of us die in hospital, a statistic that specialists in palliative medicine, like those at St Margaret's Hospice, hope to reduce.

Though St Margaret's currently maintains two residential hospice care units, the vast majority of their patients – more than 2000 – live in the community. Mr Andrewes says it is their goal to be "a hospice without walls", able to provide exactly the same care in any location. For specific populations, such as those who live alone and people with dementia, remaining in familiar surroundings gives them a sense of peace and comfort that a traditional hospice simply cannot provide. St Margaret's, like many others, cannot currently accommodate this ideal due to lack of resources, though they hope to provide this much-needed option in the future.

Some palliative care clinicians feel constrained by hospice methods and

had hoped to see more evolution within the field of palliative medicine. Sam Ahmedzai, Professor of Palliative Medicine at the University of Sheffield, became impatient waiting for change within the specialty he helped to create. So he devised a new structure for palliative medicine known as the Sheffield model of supportive care.

Not one to mince words and armed with very strong opinions about the current state of palliative medicine, Professor Ahmedzai believes the spe-

More than half of us die in hospital, yet most want to pass away at home

more and more palliative treatments," he explains. "Supportive care is needs-based as opposed to prognosis-based, that's the big difference. Palliative care and hospice care is based on the prognosis of the patient, that's what triggers the referral. Someone says 'this person's dying.'"

NEW GUIDELINES

Professor Ahmedzai's particular passion is pain management. Recently, the International Association for the Study of Pain (IASP) asked him to head up a task force in charge of creating new guidelines for the treatment of cancer pain. The task force will examine current medications as well as complimentary therapies, such as acupuncture and psychological techniques, to fully assess how each fit into the modern model of pain management.

He is keen to see progress in the area of drug choice, something he

believes has been driven largely by tradition and cost rather than research evidence and effectiveness.

"The whole of cancer pain management, particularly through the palliative care world, is all based on opioids as if these were somehow God's chosen molecules for treating pain," he says. "There are at least 50 potential receptors in the body that are part of the pathway of pain. We have drugs for twelve of those now. To only concentrate on opioids is absolutely missing the point. We should be using the whole range of drugs."

Perhaps the strongest point that Professor Ahmedzai makes is that palliative medicine is not without creatures of habit but, unlike other fields of medicine, it simply cannot afford to indulge this tendency. "The rest of healthcare had to move on. You can't just keep doing the things you've always done because it makes you feel comfortable," he concludes.

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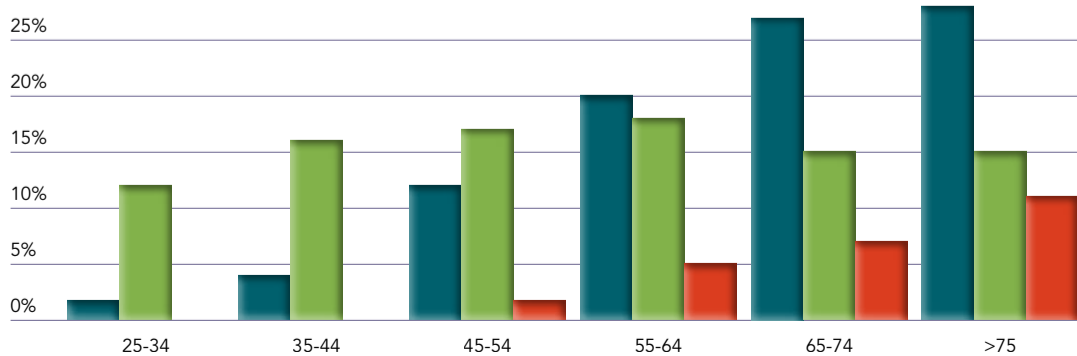
cialty should be regulated and funded by the NHS, and not left in the hands of charitable organisations, though he admits they do an excellent job. Most importantly, he believes palliative care – alleviating pain – should be available to everyone whether they are dying or not.

"With the traditional palliative care model, you start with curative treatment, say for cancer, and as the chances for cure get less and less you do

Age-related painful conditions and co-morbidity

With age comes pain, notably pain from arthritis, although back pain is also prevalent

■ Arthritis ■ Back pain ■ Angina



Source: Elliott et al, Lancet, 1999

Call to honour a dying wish

Everyone with terminal cancer should have round-the-clock access to a community nurse so they can fulfil their wish to die at home.

So says Macmillan Cancer Support which is calling on the Government to redirect funding and ensure cost-effective palliative care.

"Macmillan believes that people should be able to die at home if they wish and that access to a community nurse, whenever they need one, will help these wishes to be met," says the cancer charity's policy analyst Helen Rainbow.

Of the half a million people who pass away in England each year, more than a quarter (27 per cent) die of cancer. At present, most cancer patients die in hospitals (48 per cent) or hospices (18 per cent) and less than a quarter (24 per cent) die at home.

Yet most people would prefer to end their life at home. A recent Macmillan survey showed that 73 per cent would choose to die at home if round-the-clock care was provided. Only 1 per cent would want to die in hospital.

As well as contrasting with the majority of patients' wishes, institutional deaths are far more expensive than home deaths. According to Macmillan, if the trend for fewer home deaths continues, it will prove extremely costly for the NHS.

Public spending watchdog, the National Audit Office, has estimated that the average cost of keeping someone in hospital for their last year of life is £222 a day. In comparison, the average daily cost of home and community care is £28, nearly eight times less.

Macmillan says people's wishes about where they would choose to be at the end of life need to be recorded and accessible to healthcare professionals via integrated IT systems. Nursing skills need to be improved, in part through engaging specialist palliative care nurses, and teams and services need to be reorganised to provide 24/7 cover.