



## **Palliative care — from dream to mainstream**

A vision, a dream and drive started it all. Chris Dare overcame all obstacles to get into medical school as a senior student because she considered being a doctor essential to the new career that, inspired by Dame Cicely Saunders, founder of the modern hospice movement in the UK in the 1960s, she was determined to follow. So as a student embarked on her new path, Chris resolved to get Dr Saunders to visit South Africa to lecture on the topic. Several hurdles had to be overcome. Dr Saunders would not accept flying economy class (to be fair she is tall and had a back problem); she required evidence that the radiotherapy department at Groote Schuur Hospital was desegregated racially (which it was at that time); and she insisted on a public debate with Professor Chris Barnard on euthanasia (which was arranged). Having settled these issues Dr Saunders ran a highly successful series of lectures and workshops for the students and the public in Cape Town and other major centres.

Shortly after the visit by Dr Saunders the first hospices in South Africa were established in Durban and Cape Town in the early 1980s. Today there are over 50 hospices, many with satellite branches, affiliated to the Hospice Palliative Care Association of South Africa (HPCA). Since palliative care was at first largely provided and developed through hospices, it was sometimes erroneously associated only with the care of the dying.

Growing out of the hospice movement, palliative care evolved into a fully-fledged specialty in the UK in the 1980s. In South Africa postgraduate medical programmes in palliative care are offered at UCT, led by Dr Liz Gwyther. Fifteen doctors have achieved a qualification in palliative medicine, and there are a further 42 in the postgraduate medical programme. Under the auspices of the HPCA postgraduate nursing courses in palliative care, approved by the Nursing Council, are offered. The programme for Community Care Givers of the National Department of Health was developed by the HPCAs as a result of its experience in outreach programmes to people in rural settings. Currently courses in paediatric palliative care are under development.

The World Health Organisation<sup>1</sup> defines palliative care as an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness. The prevention and relief of suffering by early identification and assessment and treatment of pain and other problems, physical, psychosocial and spiritual, encompasses:

- Providing relief from pain and other distressing symptoms.
- Affirming life and regarding dying as a normal process.
- Neither hastening nor postponing death.
- Integrating psychological and spiritual care.
- Assisting patients to live as actively as possible until death.
- Supporting the family to cope during the patient's illness and in their bereavement.

- Using a team approach to address the needs of patients and their families.
- Enhancing the quality of life and positively influencing the course of illness.
- Working in conjunction with other therapies in the early stages, for improved diagnosis and therapies intended to prolong life, e.g. radiation oncology (and antiretroviral therapy for HIV/AIDS!).

At first the bulk of the patients cared for by hospice had cancer. In South Africa the increase in HIV/AIDS places huge demands on the existing services. HPCA statistics tell the dramatic tale of how these have changed. In 2002/2003 52% of the patients they cared for had AIDS, more than double compared with 1998/1999. Most frightening is the prospect of what lies ahead. Debbie Bradshaw *et al* record that in 2000 HIV/AIDS was responsible for almost 40% of premature mortality and that this can be expected to increase to 75% by 2010.<sup>2</sup> At the same time the emerging chronic diseases, including cancers, are going to increase substantially!<sup>3</sup>

The majority of health care workers have little knowledge about the need for palliative care in patients with HIV/AIDS. What is it then that they require? At a satellite meeting of the recent South African HIV/AIDS conference in Durban, Dr Debbie Norval addressed the question of pain in AIDS. She noted that pain in AIDS is highly prevalent — 98% in her study. Pain in patients with AIDS is likely to be underdiagnosed and undertreated — estimates of undertreatment have exceeded 80%. Neuropathic pains comprise a large proportion of pain syndromes encountered in AIDS, while nociceptive pains of a visceral and/or somatic nature are also extremely common.

Chris Dare developed cancer of the breast and was cared for in the hospice she had started, by people she had trained. She would have delighted at the progress of palliative care from her dream to mainstream. She would have been appalled at the magnitude of the onslaught of HIV/AIDS, but pleased that palliative care can play such a major role in its management, of which the provision of antiretrovirals is the most important palliative care treatment! These facts call for urgent state support of palliative care in South Africa.

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1. Palliative Care. *CME* 2003; May issue.
2. Bradshaw D, Groenewald P, Laubscher R, *et al*. Initial burden of disease estimates for South Africa, 2000. *S Afr Med J* 2003; 93: 682-688 (this issue).
3. Epping-Jordan JE, Bengoa R, Yach D. Chronic conditions — the new health challenge. *S Afr Med J* 2003; 93: 420-423.