# Lessons from hospices

Past-president Hugh Scurfield develops a topic raised at the ageing populations conference earlier in 2002.

HOSPICES HAVE DEVELOPED PRINCIPALLY over the last 30 years and they have been mainly directed by volunteers. Even now, 81% of the in-patient palliative care beds in the UK are provided by hospices run by charities. Hospices aim to improve the quality of life of patients who are dying, and also to help their families through this time, and the subsequent bereavement. Most of the patients suffer from cancer, a disease now responsible for at least one in three deaths in the UK.

Since my retirement in 1992 I have become involved in the hospice movement and have been very impressed – not only at what is achieved, but also at the extent of the voluntary initiative and effort.

Hospices exist to provide palliative care – defined as the active, total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and the addressing of psychological, social, and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families.

## The modern movement

The modern hospice movement started in 1967 with the founding of St Christopher's Hospice in London by Dame Cicely Saunders. Since then good people have seen the need to develop hospices throughout the country. They were initially capitalised and funded entirely from donations. Today there are 183 independent voluntary hospices in UK, each of which is formed as a charity with its own (usually local) trustees. The NHS provides 57 hospices, many of them associated with NHS hospitals, while the national cancer charities, Marie Curie and Sue Ryder, provide another 17. Nearly 80% of the hospices are run by charities and over 70% by local independent charities.

The NHS makes a contribution to the costs of independent hospices, but over the last six years the proportion of expenditure covered by the NHS has reduced from 35% to 28%. With patients receiving care totally free, the rest of the expenditure is covered by donations and fundraising organised locally by each hospice.

## Practical aspects

Hospices provide a variety of types of care, each suited to different periods during a patient's last months. The range of care provided can include:

- skilled medical care provided by doctors and nurses specifically trained in pain and symptom control, and emotional support for both patients and carers (palliative care is now a recognised medical specialisation);
- in-patient beds;
- home care;
- day centres providing social and creative opportunities, as well as assessment and treatment, often including complementary therapies and lymphœdema services;
- support for friends, family, and children, including practical advice (such as how to borrow a stairlift!) and counselling; or
- bereavement support for the family.

Each year 42,000 patients are admitted to hospices and some 150,000 are seen at home. Many more attend as day-patients and are visited in hospitals where the specific expertise of hospice doctors and nurses is well appreciated. These figures compare with the yearly total of cancer deaths in the UK, currently 155,000.

**If you want to find out more – or to help**

Go to your nearest hospice or contact Hugh Scurfield or Lesley at:

Help the Hospices
Hospice House
34-44 Britannia Street
London WC1X 9JG
Tel 020-7520 8202

A total of over 15,000 staff are employed in independent hospices. Half of these are nurses and 4% are doctors. In addition there are chaplains, therapists, social workers, as well as administrative and fundraising support staff.

Volunteers number almost 90,000, of which two-thirds work in many different roles within the hospice; the other third fund-raise by working in the shops. Each volunteer works for around half a day every week. This is a significant addition to the full-time staff.

The age distribution of the in-hospice volunteers, taken from just one hospice, but which is probably fairly typical, is:

| Age | % |
|---|---|
| 16–30 | 2 |
| 31–50 | 11 |
| 51–60 | 33 |
| 61–70 | 41 |
| 71+ | 13 |

## Sources of finance

In the last year the total income of all the independent hospices was £350m, of which only about £100m came from NHS funding. The other £250m was fundraised from charitable sources – an amazing amount. Collectively the independent hospices are far larger than any of the fundraising charities. The cost of fundraising is on average only 12.5% of charity income, or 7% of total income. This compares with over 30% for the national cancer charities. The difference is presumably due to the local nature of the charity, the feeling of local ownership of their hospice, the number of people who visit patients in the hospice, the enormous contribution from local volunteers, and the emotive cause.

Until the last couple of years the money had all been raised locally without a national presence and without a national name. Recently, however, Help the Hospices, a national charity, has taken on the mantle of providing the independent hospices with an integrated and representative voice, whether it be in discussion with government, in planning national activity, or in responding to national developments. It is interesting that Help the Hospices facilitates and enables, but does not control, giving the individual hospices a national voice, but without the frustrating hand of centralised control.

The sources of hospice income are:

| Source | % |
|---|---|
| NHS | 28 |
| Legacies | 23 |
| Other public giving | 31 |
| Trading | 21 |
| Other | 7 |

Trading includes charity shops and hospices' own lotteries. Hospice lotteries are a new phenomenon and their impact is growing. For example, at the hospice in Shrewsbury (where there is a catchment area of 450,000) we expect the lottery to contribute over £500,000 in the current year.

## Caring communities

The hospice movement represents a classic case study of the way communities have learnt to cope with their sick and dying. What is so special about these hospices?

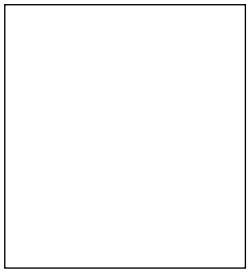
- The quality of service is superlative – and the community knows that.
- Hospices are local and each local community feels that it owns its hospice.
- The money and proceeds are used locally.
- The service is well used and appreciated by local people.
- The service is immediate and reacts to local need.
- Locals know there is a need for the service because many will have had direct contact with the hospice.
- There is very little bureaucracy.
- It is a friendly and welcoming place.
- Volunteers seem to enjoy their work and gain satisfaction from it.

Government should consider how it can adapt its centralised government into one that accepts the volunteer culture in local independent organisations, and provides equal partnerships with charities. It is not satisfactory to tell charities what to do, nor simply to say it wants more volunteers. Government has to be prepared to sit down and work alongside charities. It has to recognise the need for partnership and planning together. Hospices seek a concordat or compact that accepts and builds on the combined needs of the sick patients, the state, the volunteers, and the hospices. As yet the government appears to take them for granted.

There are many other charities and many other ways in which the growing population of 'third-agers' already contribute; I believe there is scope for many more. The culture in which volunteers flourish needs to be appreciated and developed. The needs of the young, the sick, the lonely, and the old are not yet being fully met, and older volunteers could make a much bigger contribution if suitably encouraged and organised. The benefits are clear. I suggest the hospice movement is a very relevant model, seeking as it does to provide quality of life for service users and providers alike, and grounded as it is in community resources and needs. ❑

My own awareness of the movement comes from ten years as a volunteer. I have chaired our local hospice, served as chairman of the National Forum of Chairmen of Independent Hospices, and am now deputy chairman of Help the Hospices.

How has my actuarial career helped? This is rather like answering the question 'how did my maths degree help me as an actuary?' There is lots of implicit help and comparatively little explicit. My actuarial career channelled me into leading a large business, understanding the complexities of its finance, and working with people. Hospices, with a turnover of £350m, demand leadership, business acumen, and also an understanding of how to work with government. Explicitly, I have been involved with a reversion and often with investment decisions. I was lucky also that my actuarial career left me with a pension and time to make a contribution into a very worthwhile activity. There is a saying: 'Use it or lose it.' Over the last ten years I have continued to 'use it' and I have enjoyed it.



*Hugh Scurfield is a past-president of the Institute of Actuaries and deputy chairman of Help the Hospices*