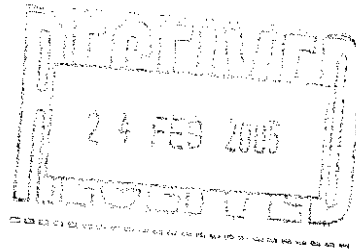




Home Hospice Inc.

41 Neil Street, Bundeena
NSW 2230 Australia
Telephone/fax: (02) 9527 1592
Email: manionha@netspace.net.au

Ms Sharon Bird, MP
Shop 501, Globe Lane
Wollongong 2500



Reg. Charity CFN 10556
ABN: 95 267 224 727

www.homehospice.com.au

Dear Ms Bird,

Thank you for including Cancer Care Home Hospice in your mail-out re the Inquiry into Services and Treatment Options for Persons with Cancer.

Having read Alan Ramsay's SMH article on Sen. Peter Cook's experience I am very interested to see some action finally in this field.

More than thirty years ago I was engaged in a two year fellowship in medical oncology at UCLA when my husband voiced his concern about the many lacunae in the medical institution's armament arrayed against cancer. I challenged him to research the issue. Over the next two years he developed our Cancer Care Program before returning to Australia and employing it against all odds over the next twenty years or so.

When, in 1980, one of those patients who had participated in the program, and very gainfully, returned with the awareness of impending death, he had one request: that he be able to remain in his own home to die.

Following that experience we had many more such requests. WHO survey showed 80% of people have that same wish. The reality is the very reverse - 80% of patients (the majority cancer patients) die in an institution. Out of our experience and convictions we established Home Hospice. The enclosed information will explain further.

Despite representations over the past fifteen years to parliamentarians - Federal and State Health ministers included - our work has been passed over and remains unfunded since the beginning, restricting its spread to other parts here in Australia and overseas, even those calling for it.

The terms of reference allow of no submission in relation to care of those dying, only to the matter of treatment.

I would submit the terms of reference should include the inquiry into the needs and wishes of the dying cancer patient and carer/family - and, indeed, the needs of the community in that event, bearing in mind the significance of the numbers in that respect.

I would not like to think we must wait another thirty years before that aspect, in turn, attracts the attention of those who can help.

We would welcome the opportunity of any further discussion on this subject should you invite us.

Yours faithfully,

(Dr.) Helen-Anne Manion, OAM

HOME HOSPICE - AN EXPLANATION

HOME HOSPICE INC. grew out of the need to enable dying people, where possible, to be able to remain at home. It does not provide palliative care or nursing, but focuses on the patient's carer and family and their need for appropriate education and support. By co-ordinating the help of friends and neighbours the carer is saved from exhaustion. This ensures the medical and nursing team has constant back-up while the patient has the comfort of home.

Home Hospice is founded on carefully thought out philosophies on the significance of home, community, human dignity and death as an integral stage of life.

The co-founders were a wife and husband team, Dr. Helen-Anne and Gerard Manion, a Palliative Care specialist and cancer counsellor. The work, begun on the Gold Coast in 1980, evolved out of their original Cancer Care Program. Its subsequent development in Sydney saw it spread to other parts of NSW and more recently in its more formal state to the Gold Coast. HOME Hospice was incorporated as a non-profit organisation and a registered charity in 1994.

THE PROCESS

Home Hospice trains a volunteer co-ordinator in a community to come to the aid at the invitation of a carer of a terminally ill loved one (of whatever age), who is usually fearful and ill-prepared for the task ahead, inexperienced and often alone.

Palliative Care and visiting nursing teams are usually already attending the patient. Friends and neighbours are standing by, eager but reluctant to intrude. The co-ordinator engages such neighbourly care in support of the carer and family. The Home Hospice educational material enables all to know how to proceed, what to expect, and how to react in this changing situation.

With friends and such practical help at hand the carer is freed to attend simply to the caring of the dying loved one who, in turn, is relieved to know the carer is not being exhausted, the burden shared by friends.

The patient is thus able to remain in the sanctuary of home, in a living environment, a place of belonging and intimacy, safe from the pain of loneliness and the loss of dignity. Loved ones, friends and neighbours respond to the opportunity to come together in solidarity and compassion. This forestalls and dissolves much grief. The intimacy of this kind of community collaboration over those final days or weeks bonds those involved.

In the best tradition of community this friendly support is freely given, seen by neighbours as both a responsibility and a privilege. The benefits that accrue to community are significant.

The co-ordinator, available throughout, oversees the situation, and remains in touch with the family beyond the death of the loved one and for as long as required thereafter.

Home Hospice has demonstrated over these many years the ability to work in conjunction with other services, e.g., community nursing, palliative care and the patient's own GP.

THE VISION of the organisation is a world in which family and their community regain their proper role in caring for the dying person.

WHO and Rotary International have commended the work. Those recipients who have been reached with this initiative applaud and support it.

The work of Home Hospice was recognised by the federal AMA with the award to Dr. Manion "For the Best Individual Contribution to Medicine in Australia 2000". She was awarded the Medal of the Order of Australia in 2002 "For service to the community and to medicine in the field of palliative care, particularly through the establishment of the Home Hospice program."