Adrienne Holzer

Patrons

His Excellency
The Governor of Victoria
The Honourable Sir Henry Winneke
KCMG, KCVO, OBE, K.St.J., QC

Lieutenant-General
The Honourable Sir Edmund Herring
KCMG, KBE, DSO, MC, ED, K.St.J.

MCM **Melbourne City Mission**

Harold McCracken Nursing Home
6 Church Street
North Fitzroy, Victoria 3068

Established 1855

Post office box 16
North Fitzroy, Victoria 3068
Telephone 481 2155

5 September 1980.

Mr D. Hill,
Anti-Cancer Council of Victoria,
90 Jolimont Street,
EAST MELBOURNE, VIC, 3002

Dear David,

I was very happy to receive the news that the Council will make $1500 available for the production of my book.

Thank you for acting on my behalf and obtaining an answer so promptly.

Yours sincerely,

Katherine

Katherine Kingsbury
Director of Nursing

RECEIVED
8 SEP 1980
To
From

Noted DH.

27th August, 1980.

Ms. Katherine Kingsbury,
Melbourne City Mission,
Harold McCracken Nursing Home,
6 Church Street,
NORTH FITZROY, VIC., 3608.

Dear Ms. Kingsbury,

I am writing to confirm my telephone conversation with your husband on Friday and have pleasure in informing you that the Council is willing to underwrite the second edition of your book to the order of $1,500

A cheque will be forwarded to you for this amount in due course.

With best wishes.

Yours sincerely,

(Miss) (Adrienne J. Holzer)
Secretary to the Council

Patrons

His Excellency
The Governor of Victoria
The Honourable Sir Henry Winneke
KCMG, KCVO, OBE, K.St.J., QC

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Telephone 481 2155

12/8/80

Dear David,

I apologize for sending the letter without the report. Also in my haste I may have failed to point out that any money lent to me to produce the report will be repayable out of sales.

Thank you for your interest

Yours Sincerely

Katherine Kingsley

Patrons

His Excellency
The Governor of Victoria
The Honourable Sir Henry Winneke
KCMG, KCVO, OBE, K.St.J., QC

Lieutenant-General
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11 August 1980

RECEIVED
12 AUG 1980
To
From

Mr D Hill,
Deputy Director,
Anti Cancer Council of Victoria,
90 Jolimont Street,
EAST MELBOURNE, VIC, 3002

Dear David,

I have been let down by 2 typists who seem over whelmed by the talk of typing for me. The proposed chapter titles will be :-

1. The Dying Patient and His Needs.
2. The Family of the Dying Patient.
3. Bereavement.
4. Hospices.
5. Control of Distressing Symtoms in the Terminally Ill.

Incontinence and the chapter on Home Maker Services (p.72) will go to the appendices.

The book will be useful for lay people and professional people alike. Some have suggested a separate edition for lay people but I disagree on two grounds. 1. Too much work for me. 2. I am anxious to encourage all people to be informed and understand alternatives. If the meaning of a word is over their head and they want to know about it, that could be a good chance to talk to the local doctor.

The cost (without typing) to produce 1000 paper backs about 8" x 5" is $3000 including the Government Bounty. It will sell for $7 a copy plus postage and I am willing to repay any money I borrow. I only ask that I can repay at the rate the book sells.

Thank you for your interest.

Yours sincerely,

Katherine

Katherine Kingsbury

Thank God for men who can be moved to disquiet".....Zeus

INTRODUCTION

" Studies indicate that 80% of patients who are terminally ill would choose to die at home, but more than 80% are actually institutionalized when they die."
(Marion Steinberg)

There is a growing resurgence in the community for an alternative to institutional care - a demand for a real and informed choice about where to die. The information that forms the basis for this book was obtained when I travelled to the U.S.A., the U.K., Canada and Holland as a Winston Churchill Fellow (1978). I have learned much since then to broaden my understanding of the need for adequate domiciliary services and for better care of the dying. I hope this revised edition will stimulate health professionals and lay people, cancer sufferers and their families to believe that it is not a difficult task to improve existing services and to introduce new ones.

The extraordinary contributions of this complete support which includes medical, spiritual, psychological and social assistance for the patient dying of cancer is becoming well known. Nevertheless the potential for abuse of the hospice system does exist. The early hospices had the good fortune to be developed and administered by persons of high dedication, competence, compassion and integrity. The need for the hospice and the success of the first models have led to a great interest in this subject by health professionals and the public. These are positive developments, but it must be kept in mind that critical reviews and evaluation must be made continuously to prevent abuses of the system. The hospice program is too important to allow its integrity to be jeopardized by a blind acclaim of its objectives that preclude appraisal of problem areas. Cancer sufferers in Australia and their families must not be left unsupported to demand that their care equals that offered in modern hospices in other countries.

It is feasible that most, if not all people should be able to fulfil their desire to be at home in a familiar secure environment, to be pain-free and to be well cared for.

My thanks are due to the Perpetual Trustees Association for their grant given to help produce this book. The directors of the Brotherhood of Saint Laurence financially assisted me to produce the first edition and they have shown their support and faith in my work by offering further financial help.

My earlier work as Supervisor of Fitzroy Council's Domiciliary Services for four years until 1979 was a time of motivation and encouragement to develop domiciliary services beyond what was then available.

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The acceptance of people throughout Australia of my Churchill Report led me to write this revised 2nd edition.

Whenever I met people or spoke to audiences I was told that better care for the dying and their families was desperately needed. People still speak and write to me, often in a self conscious and embarrassed way, of their profound lonliness, their isolation and the increasing intensity of their grief after the death of someone close. Resources to help vulnerable survivors are almost non-existant in this community. The average person simply does not know where to turn for help after those first weeks when responsibilities have to be undertaken and when relatives and friends resume their own lives.

Many people in Australian cities are now meeting to plan ways to offer modern hospice care - fourteen years after it was first offered to dying patients in England. This is an indictment of those in Australia who knew years ago that there were better ways to care for the dying and their families, and did not act. It is heartening to see that change has begun at last.

The Melbourne City Mission is a voluntary organization, justifiably proud of its long history of community service. These services usually offer innovative care for those in need.

When, through my Churchill Report the concept of modern hospice care came before them, the Melbourne City Mission made a commitment in principle to develop such a service. After tireless efforts by the Mission, funding from the Kellogg Foundation (USA) and the Australian Federal Government was obtained to develop a demonstration in modern hospice care for 2 years.

In this 2nd edition I have chosen to emphasize the three fundamental componants of modern hospice care. Care for the dying, care for their families and care for staff. I am now committed through the Melbourne City Mission to the development of these services.

Over the years a great body of knowledge has been amassed in Australia as well as overseas about the needs of dying people. In Australia there are a great many books, papers and articles, speeches, lectures, seminars and courses. Unfortunately our practice experience in Australia and our understanding of their needs have not grown alongside our theoretical knowledge.

My son Damien gave assistance in writing this book by offering constructive criticism of the form of its content. My colleague Irene Renzenbrink and I have shared ideals and aspirations. Her advice has been so valuable when writing that the book would not have been completed without her assistance. Irene's insight into the needs of staff and patients has strengthened the courage of my conviction. She and I have both known the despair of feeling alone and lonely in busy hospitals where staff who are aware of institutional deficiencies and

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and of the unmet needs of patients, families and care givers can feel trapped and helpless in a system which is geared to curing.

A great deal has happened in that short time since my report was first published. Despite broad acceptance of the ideas expressed in the report, then, the basic problems still remain in Australia for those who are dying and for those who care for them, whether at home or in an institution.

Rough draft, but not too rough!

DYING PERSON AND HIS NEEDS

Death is probably the loneliest experience any of us will ever have to face. People with advanced malignant disease~~s~~ have very special needs -needs which are beginning to be met by open minded people whose sensitivity has been reawakened by enlightened social concepts. There was a time when hospital staff, because of social and institutional constraint, failed to recognize the unique suffering experienced by dying people and those who are close to them.

Possibly the most important concern of the dying patient is to be physically comfortable. The relief of physical discomfort and pain not only frees the dying person to consider other personal matters, but also makes life potentially bearable and sometimes can make it enjoyable.

It has been said that there has been too much talk amongst people caring for the dying, about psychological and emotional problems and too little about the simple matter of making patients comfortable. Until dying people are clean, dry and comfortable, it is quite inappropriate to consider talking with them of other matters. This is not to say that time spent sitting quietly, without anxiety, sharing the patient's concerns is not essential, but it is better that counselling should follow physical care. Experience has demonstrated that most dying patients are not demanding; they require a minimum of specific attention, but do like to have someone around if they have a desire to talk or need help. In general there is a narrowing of interests and concerns, with a limited attention span and long periods of quiet wakefulness or light sleep between brief periods of activity or expressed need or discomfort.

The emphasis in hospitals tends to be on complex technical care and investigations. In the last months of life we must not be distracted from simple nursing measures which provide comfort and do not necessarily exclude the possible use of more sophisticated methods of treatment. Doctors often insist on specific treatments which in terms of nursing practice are in conflict with the real needs of the dying person. For example, observations of temperature, pulse and respiration are often requested but are no longer relevant. Some of the patient's needs, however, may be to feel his mouth moistened, his nausea relieved, his skin massaged to prevent pressure. Insomnia is distracting and must be resolved even though it is often a complex matter perhaps involving pain, anxiety, depression and being in an unfamiliar environment. Those who have lost their appetite can dread meals, meals which are often unappetizing and served at inflexible times. These patients who usually have limited mobility and reduced fibre in their diet can be distressed by constipation. (See appendix E)
The causes need to be identified and the patient's expression of discomfort must be believed.

The voice of the dying person is seldom heard. So often staff in hospitals assume they know the patient's needs and believe they know how those needs can be met. The devastating impact of the institutional environment on the patient

with dying people and their families. When caring for the dying remember it often under estimated. Loneliness and despair, about separation from family and friends, the loss of privacy and the lack of control over personal decision making processes can lead to a sense of alienation. Alienation in itself can lead to apathy, depression and a feeling of hopelessness. The dying patient may no longer feel a part of the real world. This fundamental problem of alienation is exacerbated by mental and physical isolation, avoidance and rejection by staff even when family members remain supportive. Regimentation in the form of scheduled meals, visitors, bathing, dressing and sleeping is a further depersonalizing influence. Opportunities for honest, open and personal communication are limited by lack of privacy and tensions in relationships with family and staff.

Patients often want to hear the truth about their future but not the truth that is brutally told, ignoring sensitivities. I doubt that patients should ever be told other than the truth when they ask - the issue is how to tell and how much to tell each time. False reassurances are often detected by patients although they might not admit this in an attempt to protect the people caring for them. Staff may offer patients technical explanations that can't be fully understood especially in times of emotional turmoil. In this way they avoid closer and more painful personal contact which could still be regarded as "unprofessional". There is growing evidence that most patients and families value most highly their contact with staff who are prepared to share their vulnerability and who dare to become involved. It is also becoming increasingly clear that staff gain a great deal from this involvement.

Dying is continuous with people's lives. Some dying people may wish to express feelings of anger and sadness which those around them may find unsettling, others may wish to be left alone in peace keeping their innermost thoughts and feelings private. It is important to respect individual ways which dying people develop to deal with their disease and the impact it has on their lives. (Include case examples - actress, old lady, - p.26.

There may also be an anxiety about "unfinished business" This may be unfinished financial business such as making a will or handing over financial responsibilities to survivors. It may also mean the unfinished business of settling old quarrels and saying goodbye.

Some people may need help and encouragement to communicate their needs. As Dr. Elizabeth Kubler Ross has taught, some patients use non-verbal symbolic language. These people are often those with the greatest fear and need, yet care givers often fail to understand their meaning. Some useful questions to elicit how much a patient wishes to talk are "Are you worried about yourself?" "How is your family affected by the illness?" "How serious do you think the illness is?" The conversation should be led and ended by the patient.

With the upsurge of interest in the area of death and dying there is a danger that helpers can become over-zealous and intrusive and fail to appreciate the fluctuations in the patient's desire to share his experience. On the other hand some people have a natural intuitive ability to establish rapport with dying people and their families. When caring for the dying remember it uires a thoughtful, sympathetic person who can work in harmony with the patient's passage through the stages of his illness.

In the past decade there has been an unprecedented growth of knowledge about the experience of dying. Dr. Kubler Ross has developed a valuable conceptual framework for understanding the process of dying and our customary ways of dealing with death. She has described five stages which may occur when a person is dying. They include shock and numbness, the patient's denial of his IMPENDING imminent death, his anger, his willingness to bargain for more time, depression and preparatory grief and sometimes peace and acceptance. A common misconception about these stages is that each must be experienced and that they will occur in the sequence described. To believe this is to do a grave injustice to Dr. Ross's work. Patients do not necessarily pass through each stage, do not necessarily reach the final stage of acceptance and cannot be pushed forward through stages. There may be a blurring of stages or even a reversal and allwe, as care givers can do, is to be patient, supportive and listen well to what the patient says to us. Dying persons demonstrate a wide variety of emotions that ebb and flow throughout our entire life as we face conflicts and crises. It may be misleading to search for and determine stages of dying. We must not make the patient conform to our idealized concept of dying, but respond to the person's actual dying experience. (Pattison).

Unrelieved physical pain is dreaded by us all but the real pains of the dying are also grief, despair, fear and anger. There are other writers who say that rather than moving through specific stages the physician needs to be adept enough in handling the physical pain to be able to concentrate on the real work of sharing and relieving these other feeling s. The pain of the dying has been described as a great inner longing, a feeling of separation, lack, sin or inadequacy. For those with a definite religion the way is sometimes easier, but most people are only vaguely religious or have no faith. More people now only believe in materialism - the body and the personality, yet the doctor has to answer their questions and face their fears with them, quite naked of comfortably formalized ideas.

In sacred doctrine Man was seen as God's creature, fashoined after his image from the dust of the earth. Man's death, no less than the life that ~~was~~ HAS BEEN breathed into him was an act of Divine will. Within such a theological structure man could stand secure in the knowledge that death was a personal matter between God and himself. The very purposefulness of his death placed him at centre of existence and elevated him above all other creatures as the principal subject of creation. As part of a Divine plan, death was the brother of life and as such could be confronted openly, spoken of freely, and treated as a natural phenomenon. For western society the recognition of death was a prime requisite for life as well as an integral dimension of personality identity.

Traditional rites for the dead symbolized and gave expression to theological beliefs. They served to reinforce the social bonds of the group and in so doing, compelled recognition of its elemental constituent - the individual. Ceremony for the dead thus served to link God, man and society.

Today we have come to a point in our history where we react to death as we would to a communicable disease. Death no longer is viewed as the price of moral trespass or as the result of theological wrath; rather, in our secular world, death is seen as the consequence of personal neglect or untoward accident. Death is now a temporal matter. Like cancer or syphilis, it is a private disaster that we discuss only reluctantly with our physician. Moreover, as in the manner of many contagious diseases, those who are caught in the throes of death are isolated from their fellow human beings, while those who have died are hidden quickly from view. (Fulton)

Whatever one's philosophy, all the great teachers have told us that a dying man must prepare for death and that this preparation should never be interfered with. It is realised that as well as the family grieving, the dying person also grieves. This person is losing everything - family, friends, a home and favourite personal things. Care givers must give the patient every opportunity to express grief and other feelings such as guilt for things left undone or unrectified and even fear of the unknown. (LAMERTON)

Hope in one whose life is hopeless seems a paradox, but we must always allow for hope in dying people. Hope at the beginning of a serious illness is different from hope at the end of life. This hope can be a projected wish for the patient's children, or desire for a little more time and a heartfelt hope that care givers won't desert. Even though the dying person is beyond all cure, reassurance is needed verbally and implicitly that he will not be abandoned and that he will not be left alone to face the moment of death.

file

MELBOURNE CITY MISSION

DEMONSTRATION HOSPICE CARE UNIT

IN NORTH FITZROY, MELBOURNE.

MAY, 1979.

Roy Jackson
Deputy Director

CONTENTS ::

* * * * * * *

1. Background of the Agency:

1.1 Melbourne City Mission has been established since 1855 and is therefore, one of Victoria's oldest social welfare agencies.

. Our agency's work and objectives are firmly founded upon Christian ideals. Expressions of these are evident in the ever present concern for the total needs of the people being cared for. However, it is worth noting that we endeavour to major on interacting with people with a view to their acknowledging their worth and to achieving their potential to make a contribution to the life of society in general and those near to them in particular.

1.2 Our programs incorporate services through various Centres in Mebourne to :

Children from broken homes
Socially handicapped teenage girls
Homeless Youth
Homeless and alcoholic men
Families at risk
Aged persons.

1.3 In respect to aged persons, the work of Singleton Lodge, Collingwood, dates back to 1872, and our management role in that work commenced in 1924. Some 23 years ago, in 1956, soon after the passing of the Aged Persons Homes Act, we entered into the development of what was then a unique type of concept in caring for the aged. This was the construction of the Judge Book Memorial Village. Over the years the Village has expanded and we now accommodate and care for 250 people on the 14 acre Eltham site, in independent living units, hostel units, and nursing home accommodation.

2. Birth of the Hospice Idea in our Agency

2.1 Much of our work has been centred around the city and inner suburbs of Melbourne, and our administration offices, by design, have always been close to the agency's activities. As a result, we have developed a first hand awareness of the many and varied needs of the critical inner urban areas. Whilst we could never hope to meet all of those needs, we have been able to direct our attention to concerns within the capabilities of our expertise and our resources.

2.2 One such prominent need to emerge was that of a nursing home for aged persons within the suburb of Fitzroy. Fortunately, by virtue of a mutually advantageous agreement with the Uniting Church, we were able to relocate our administration offices in North Fitzroy in March, 1976. Not only did this give us a convenient office, but it presented us with an adjacent piece of land upon which we planned to develop a nursing home.

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2. Birth of the Hospice Idea in our Agency

2.3 We have consciously adopted in our agency, a policy of slotting our services into the program of services existing within the community. Therefore, we presented our thoughts to the Fitzroy Aged Services Committee. This is an excellent resource group whose membership includes representatives from :

Fitzroy City Council Domiciliary Services
Brotherhood of St Laurence
Depaul Health Centre
St Vincent's Hospital Home-Care Service
St Vincent's Hospital Social Work Department
After Care Hospital
Cameron House
Royal District Nursing Service
Mount Royal Geriatric Hospital

and, of course, our own agency.

2.4 The group was actively involved in the total planning process and, we believe, a better design and a more considered philosophy for the nursing home resulted. The outcome was a design for a 50 bed nursing home, which is now well into construction and should be at a stage of practical completion by the end of this calendar year.

2.5 One of those attending the Fitzroy Aged Services Committee meetings, was Sister Katherine Kingsbury. Sister Kingsbury's work interests were, and are, in the field of co-ordinating the Fitzroy Council's domiciliary services and out of this arose a deep concern for those with terminal illnesses whose needs, she felt, were not being adequately met by the available resources within the community. So concerned was Sister Kingsbury that she applied for and was successful in obtaining a Churchill Fellowship which enabled her to study this subject overseas in 1978. On her return to Australia, Sister Kingsbury documented her findings in a publication entitled -- "I Want to Die at Home", sub-titled -- "A study of alternative models of care for the frail aged, the handicapped and the dying".

2.6 It was natural that the interest of each member of the Fitzroy Aged Services Committee in the publication, was high. The concepts of care which were described were found very compelling by our Director, Rev. Bruce Addison, and he presented our General Committee with a submission seeking approval to develop a means of introducing the concepts of caring for terminally ill people into our agency through a suitably designed program. The General Committee expressed a lively interest in the concept and asked the Director to undertake further enquiries and to prepare a report.

2.7 These particular caring concepts are embodied in the term "hospice care" and have been used to effect in Europe and North America.

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3. What is Hospice Care?

3.1 Hospice is a word which originated in the time of the Crusades in the Middle Ages

"It denotes a place designed for the provision of comfort and hospitality to travellers along the road. In the case of the hospice movement, the road is the course of terminal illness and the travellers are the cancer patients and the families of those patients".(i)

3.2 This statement introduces the fact that in general, the hospice movement is directed towards terminally ill cancer patients -- and our agency is thinking in terms of a similar direction of concern in this submission. The term "hospice care" is also used synonymously with the term "palliative care".

3.3 Sister Kingsbury in her publication, records a very succinct description of what a hospice care program involves.
She writes:--
"Hospice is a program which provides palliative and supportive care for terminally ill patients and their families, either directly or on a consulting basis with the patient, physician or other community agency such as a visiting nurse association.

"The whole family is considered the unit of care, and care extends through the mourning process. Emphasis is placed on symptom control, preparation for, and support before and after death. Services must be available 24 hours a day, 7 days a week."(ii)

3.4 The above paints the hospice picture on a broad canvas. However, Dr. Lack in her paper, "Philosophy and Organisation of a Hospice Program" identifies the elements evident in this system of health care delivery. They are:--

"a) Co-ordinated home care - inpatient beds under a central autonomous hospice administration.

b) Physician directed services.

c) Control of symptoms (physical, sociological, psychological, spiritual).

d) Provision of care by an interdisciplinary team.

e) Services available on a 24 hours-a-day, 7 day-a-week, on-call basis with emphasis on availability of medical and nursing skills.

f) Patient/family regarded as the unit of care.

g) Bereavement follow-up.

h) Utilization of volunteers as an integral part of the inter-disciplinary team.

i) Structured staff support and communication systems.

j) Patients should be accepted to the program on the basis of health needs, not ability to pay." (iii)

3. What is Hospice Care?

3.5 A copy of Dr. Lack's paper and a statement on the "Essentials of Hospice Care", written by Dr. C. Saunders for the 1977-78 Annual Report of St Christopher's Hospice, London, are both included with this submission as Appendices A and B respectively.

3.6 These papers emphasize the need for service co-ordination to maximize the use of available resources. Such resources would include physicians, psychiatrists, nursing staff (bedside and domiciliary), social workers, paramedical staff, ministers of religion, domestics, office and administration personnel, volunteers and other community based services and facilities. Professionals and non-professionals, paid and unpaid staff, are welded together by a common concern for their patients, and a paramount desire to deliver quality health care with sensitivity and empathy.

4. Public Interest in the Hospice Movement

4.1 Although the 1960's saw the emergence of the hospice movement in England and the U.S.A., it has only been in very recent times that people in Australia have given attention to the subjects of death and dying, and bereavement. Visiting lecturers such as Dr. Elizabeth Kubler-Ross have been greeted with an overwhelming response from the general public and the media and this same response has been experienced by Sister Kingsbury as she has moved around the State speaking at meetings. Health professionals, concerned relatives, government officials, members of parliament and Ministers of the Crown are among those who have expressed deep interest in her publication and her personal presentation of what hospice care is.

4.2 Such is the ground swell of interest that our agency believes the time has arrived when a practical demonstration of the hospice care concepts should be undertaken and to signify its commitment to hospice care, it is prepared to move towards setting up a pilot project.

5. The Demonstration Project Model

5.1 Over the past few months, members of our staff have been examining ways and means of launching an appropriate project. It has not been a case of whether we should embark upon it, but a case of determining how and when,

5.2 In our investigations, we have grappled with the wisdom of undertaking a large project as against a smaller unit. We have considered the siting of the in-patient component of the hospice unit in relation to its likely catchment area. Further, the costing of a demonstration unit, particularly in the area of staffing, has been difficult, for the Australian scene is not immediately compatible with that of overseas. Bound up in all of these deliberations was concern as to how many patients and families could be cared for at any one time. Each of the factors considered had a bearing on the others. Consequently, the task of merging our thoughts required many modifications before we arrived at what we believe to be a suitable approach.

5. The Demonstration Project Model

5.3 It was only natural in the development of our approach, for us to draw upon whatever advice we could, and to study pertinent overseas literature and reports. A by-product of the investigations was a reinforcement of our view that hospice care is a very humane and sensitive program with very apparent economic advantages over more conventional care delivered in and through acute hospitals.

5.4 The general philosophy of acute hospitals is focused on making sick people well. This results in a misunderstanding of, and an inadequacy in, the handling of terminally ill patients. It is not unusual to find a dying patient isolated in a corner of an intensive care ward, surrounded only by numerous life-support facilities. Staff are continually at a loss to know what to do or say. As Dr. Wessel puts it :

"....many professional people have failed to come to terms with the inevitability of dying. This hinders their ability to think and act in a way that helps and comforts a patient who is in the midst of this very struggle." (iv)

5.5 The size of the target group for the demonstration project :

5.5.1 We settled upon a group of 30 patients and their families. This was thought to be large enough to be accepted as a valid demonstration group and yet small enough for us to feel our way through the establishment of our caring guidelines. We also envisaged that the catchment area for patients would roughly coincide with that of the St Vincent's Hospital.

5.6 The in-patient beds component

5.6.1 The construction of the North Fitzroy nursing home, corner of Church and Nicholson Streets, presented us with an ideal vehicle for the in-patient component of the demonstration. It is being constructed in a strategic geographic area, well served by community based facilities, and near to almost all of the large acute hospitals with many specialised resources.

5.6.2 We felt that we should set aside 10 of the 50 beds for the demonstration. This number bears a viable relationship to the size of the target group and fits in well with the design features of the nursing home. Of these beds, we would anticipate that 8 would be permanently occupied by patients in their last days or weeks of life and 2 would be used for more short term purposes, such as family relief or the stabilization of medication.

5.6.3. A point which should be made here, is that the patients would fall into the category of nursing home patients in terms of the appropriate Act.

5. The Demonstration Project Model

5.7 Staffing

Staff positions, their main areas of concern and the extent of their involvement, are set out below:--

Position	Comments
Medical Director	A part-time appointment, approx. 2/3rds, of a physician. Both in-patient and out-patient activities will be involved. His attention will be directed towards disease management, pain control and family support.
Psychiatrist	A sessional appointment providing professional services to both patients and staff. Because of the emotionally draining aspects of the work, the service to staff will be a most important feature.
Director of Nursing	In the initial demonstration, this position will be described to cover both the nursing home and the hospice units. It is believed that approximately half the Director's time will be required to oversight the nursing services and to be a part of the total caring team.
In-patient Nursing staff	One S.R.N. and one R.N.A. will be required for each shift to provide adequate intensive care.
Domiciliary Nursing staff	When the demonstration is fully underway, it is anticipated that a total of 60 hours per week will be required from these team members. Home visits in hospice care are of necessity much longer than under normal circumstances. Each could take 1½ hours.
Social Worker	A full-time appointment will be necessary to cope with the complexity of problems associated with the patients and their families.
Occupational Therapist	A sessional appointment which will serve the patients at home as well as in the in-patient setting.
Physiotherapist	Similar to the Occupational Therapist.
Receptionist/ Clerk/ Secretary	A single full-time appointment which will deal with initial and subsequent telephone calls, maintenance of records and statistical data and general office duties. Hospice care is a team approach and this appointee will be a member of that team.
Support staff	Domestic, catering and laundry staff consistent with requirements and in some cases, undertaking shared duties in the nursing home.
Ministers of Religion	These will be drawn either from the local community or from the patient's own locality, whichever is the more appropriate. The program will require these personnel to be educated in the team approach to caring.
Co-ordinator of Volunteers	A half-time appointment which is necessary to cope with the recruitment and management of the work of volunteers.

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5. The Demonstration Project Model

5.8 General

5.8.1. As already indicated, we see the hospice project as being a part of the community based services of Fitzroy. Wherever possible the community resources will be tapped, provided, of course, that in doing so we are not being inconsistent with the overall goals of the unit.

5.8.2 Another feature of hospice care is the enlistment of the assistance of members of the patient's family and that of volunteers. This is a most effective resource for the caring program.

5.8.3 We envisage our hospice project as being the seed from which a larger one will be developed, possibly near to the North Fitzroy nursing home.

6. Objectives and Criteria of the Demonstration Project

6.1 Our agency has an overall objective to undertake a demonstration project on hospice care with a view to establishing the concept as a viable alternative to present methods in both the areas of quality of care and service economies.

6.2 However, we have not developed detailed objectives as yet. With this in view, we have appointed a Hospice Committee to look into the very critical aspects of formulating the objectives of the unit, establishing the criteria of entry for patients and generally developing the overall philosophy and the machinery for bringing the unit into operation.

Set out below are the goals of an overseas organization which has experience in the domiciliary components of hospice care:--

" 1. To help the patient to live a fully as possible.
2. To support the family as the unit of care.
3. To keep the patient at home as long as appropriate.
4. To educate health professionals and lay people.
5. To supplement, not duplicate, existing services.
6. To keep costs down. " (v)

6.3 These are but the guidelines of one agency and when committed to paper, they inevitably do not convey the warmth and deep sense of caring which permeates the whole of that caring team. We trust that when we come to writing our objectives, we may be able to adequately express the compassion we have for the dying and their families.

6.4 The membership of the committee which will be wrestling with the weighty problems of our hospice program comprises --

Mr. B. Clarke	Medical Director, St Vincent's Hospital Intensive Care Unit
Dr. R.B. Scotton	Director, Planning and Research, Victorian Health Commission.
Miss N.E. Bryan	Director, Royal District Nursing Service.
Mr. J. Crisp	Executive Director, Australian Council on the Ageing.

6. Objectives and Criteria of the Demonstration Project

6.4 The membership of the committee (continued)

Dr. B. Rumbold	Minister, Box Hill Baptist Church, who has completed post-graduate studies in Dying and Bereavement.
Miss D. Wilson	Social Planner, Fitzroy City Council.
Miss H. Goodman	Social Worker, Alfred Hospital Haematology and Medical Oncology Unit.
Dr. A.R. Moore	Senior Lecturer, Department of Surgery, University of Melbourne, Royal Melbourne Hospital.
Rev. B.S. Addison	Director, Melbourne City Mission.
Miss K. Kingsbury	Director of Nursing elect, Melbourne City Mission.
Mr. R.W. Jackson	Deputy Director, Melbourne City Mission.

7. Research and Evaluation

7.1 We are currently exploring ways of injecting a research and evaluation segment in our hospice program. Dr. R.B. Scotton, Director, Planning and Research of the Victorian Health Commission, is assisting us in this regard. Further, we will be making a submission to the Federal Department of Health for a grant for this research and evaluation component. In doing this, we are acting on the advice of officers of the appropriate section of the Department.

7.2 The results of our project and the knowledge gained in undertaking it, will be made available to all interested agencies and individuals.

8. Financial Projections

8.1 Our estimates of the cost of the project, indicate that our shortfall will be approximately $46,000 in 1979/80, $97,000 in 1980/81 and $52,500 in 1981/82 -- a total of $195,500. These figures are based on the assumption that the project will commence around the latter part of February, 1980 and will be completed in December, 1981.

8.2 In making our calculations, we have assumed certain "lead up" times for employing staff and having patients come into care.

8.3 No comparisons have been made with the costs of caring for dying patients under the present health care systems. This will be one of the tasks built into our evaluation procedures.

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9. Some Steps taken In Developing the Project

9.1 Correspondence has taken place with The Federal Minister for Health, Mr. Ralph Hunt, and other key people. As a result, we have received encouragement from the Federal Acting Minister for Health, Mr. Wal. Fife, and officials of both the Federal and State Departments of Health, and leading citizens.

9.2 Preliminary interviews seeking advice have taken place with --

Mr. R. Rofe, Mr. I. Manton, and Mr. W. Meggitt	Federal Department of Health, Canberra;
Mr. P. Hede	Federal Department of Health, Melbourne;
Dr. R. Scotton, Dr. J. Wiseman and Mrs M. Shaw	Health Commission, Melbourne.

9.3 In every instance, we have been congratulated on our approach to develop a demonstration unit and encouraged to proceed further with our investigations of funding sources.

10. Funding Avenues

10.1 Federal Government - Department of Health (Deficit Financing)

10.1.1 We can apparently be assured of deficit financing support up to the normal approved level for the 10 beds in a nursing home setting. However, the additional expenditure incurred in providing more intensive bedside care to the patients, and support services such as counselling and consulting to the patients and families in the nursing home itself, do not fall within present deficit financing guidelines.

10.1.2 A submission has been made to the Department with a view to determining if the deficit financing guidelines can be extended to embrace all in-nursing-home care in our hospice program.
If the Department agrees, it would mean that $59,000 of our total shortfall of $195,500 would be met.

10.2 Federal Government - Department of Health (Health Services Research and Development)

10.2.1 A submission for a grant to research and evaluate the hospice program will be documented as soon as we can establish a protocol. We have reason to believe we could be successful with our application but we have no firm undertaking.

10.2.2 If all other avenues of funding fail, we could apply for a grant to cover the total project. It would seem there is precedence for obtaining a grant in these circumstances, but the indications given to us to date are not very encouraging.

10.3 Federal Government - Department of Health (Community Health)

10.3.1 No funds are directly available through this division. In every instance, State Governments put forward programs to the Federal Government and funding is approved to States on the basis of those programs only.

10. Funding Avenues

10.4 State Government - Health Commission (Hospitals)

10.4.1 We are investigating the possibility of having medical, paramedical and/or social work staff seconded to the hospice care unit from ~~for~~ one of the major city hospitals. These enquiries are in their very early stages at present and we have no idea if they will be successful.

10.4.2 Involvement of a public hospital at this level could be a very practical way in which the State Government could make a financial contribution to the program. The total amount involved is estimated at $100,000. As this funding would come within the scope of Federal/State cost-sharing arrangements, the two governments would share the expenditure.

10.5 State Government - Health Commission (Community Health)

10.5.1 If any funds were to be allocated directly through this division, we are led to believe they would be of a "topping up" nature only. We would be required to make an application setting out a schedule of funds received or promised, seeking assistance for all or part of the balance.

10.5.2 We intend to approach the appropriate domiciliary nursing service, probably the Royal District Nursing Service, to determine if secondments could be arranged to cover the community nursing component of the program. Once again, this would present an opportunity for the State Government to be involved financially. The estimated value of the domiciliary nursing component is $36,500.

10.6 Trusts, Donations, etc.

10.6.1 These avenues of funds have not been widely explored. Consequently it is difficult to assess the anticipated level of financial interest.

11. Conclusion

11.1 "Good medical care, skilled nursing, understanding pastoral care, use of auxiliary services such as physiotherapy, social work, and home care programs, acceptance of help from volunteers and patients' families, attention to the needs of the families -- these are the elements of total care that must be developed for providing competent palliative (i.e. hospice) care." (vi)

Hospice care is new to Australia. Its value has been proved beyond doubt overseas, and our agency is committed to seeing that the reality of this statement is demonstrated in this country.

We believe we will achieve this objective given the appropriate support, both financial and moral, of the Australian Government.

* * * *

APPENDIX B.

ESSENTIALS OF HOSPICE CARE

1. *Management by an experienced clinical team* integrated into the work of the whole medical community and giving effective continuity of care.
2. *Understanding control of the common symptoms of terminal disease, especially pain in all its aspects* will enable patients to live to their maximum potential and will at times herald unexpected remissions and/or the possibility of further active treatment.
3. *Skilled and experienced team nursing* which calls for confident leadership by the ward sister and easy communication among its members.
4. *A full inter-disciplinary staff* meeting frequently for discussion. The doctor does not relinquish his clinical responsibility but a member of another discipline may sometimes assume leadership for a particular patient or family.
5. *A Home Care Programme,* active or consultative and involving all the relevant disciplines, must be developed according to local circumstances so that it can be integrated with the hospitals, the family practices of the area and its own beds.
6. *Recognition of the patient and his family as the unit of care* and of the family as part of the caring team. They may need support, not only in meeting physical demands but also in their own search for reality and meaning.
7. *A mixed group of patients.* Although the current interest in hospice care in the U.S. is especially concerned with "the dying cancer patient and his family", a good community is usually a mixed one and hospices may include among their concerns those with long-term illness, chronic pain and, in some cases, frailty and old age.
8. *Bereavement follow-up* to identify those who are especially vulnerable and to give support in co-operation with the family doctor and any local services which can be involved.
9. *Methodical recording and analysis* will monitor clinical practice and, co-ordinated with relevant research where possible, lead to soundly based practice and teaching.
10. *Teaching in all aspects of terminal care.* Special units should be a resource, stimulating initial interest, giving experience and passing on tested knowledge to others in both general and specialist fields.
11. *Imaginative use of the architecture available.* Many hospices will not be able to build anew and have to adapt a building in order to combine privacy with openness and community and a sense of home with efficient operation.
12. *An efficient and approachable administration,* essential to any field of human need and care, is here required to give security to patients, families and staff. Efficiency is both comforting and time saving. So far, hospices have shown that their operation is cost effective as well as appropriate and humane.
13. *A readiness for the cost of commitment and the search for meaning.* Devotion has been an outstanding characteristic of past and present hospices. Willingness to face this demand has a fundamental bearing on the way the work is done and the stability of the staff.
    A Christian Hospice will be aware of the presence of the crucified and risen Christ in the midst.

This list of essentials owes much to Florence Wald and the International Work Group on Death, Dying and Bereavement and to Dr.

APPENDIX A.

SYLVIA A. LACK, M.B., B.S.

Philosophy and Organization of a Hospice Program

The Hospice programs now in existence in Britain and in the United States in New Haven, Connecticut, have grown out of the needs of the patients and their families in the communities which the hospices serve. It has always been a basic tenet of hospice personnel that it is the patients themselves who can most adequately express the type of care they need. One such patient was Stuart Alsop. Suffering from leukemia, he wrote a book on his experience called *Stay of Execution*. He describes his experience of terminal cancer patients "dying agonizing deaths" and asks that they be allowed "the illusion of painless pleasure".

It has been my experience, as a physician, that given the appropriate program of care, pain relief is certainly available and something better than illusion; something real for the patient and his family. The suffering and perplexities of the terminal patient and his family are well documented. For example, from Cancer Care, Inc., New York, comes the report on the impact, uses, and consequences of catastrophic illness. This report describes vividly with revealing case histories, individual comments, and statistics. Some of the physical and emotional costs of such illness upon patients and their families are often and sadly exacerbated by financial burdens.

Of course, cancer is not the only disease which can so cripple a family, but it does seem to exemplify vividly the problems a dying patient faces. Most discussions on caring for the dying seem to take for granted that it is cancer of which we speak. Not all the patients in the British hospices have cancer nor are patients only admitted to die. Hospices with a Home Care program, such as St. Joseph's and St. Christopher's have as many patients at home as in their wards. In New Haven, we are currently functioning as a Home Care program with inpatient facility in the design stage. The main concern of a hospice program is the management of terminal disease in such a way that patients live until they die, that their families live with them as they are dying—and go on living afterwards. The heavy toll in terms of public health caused by bereavement under our present system is increasingly recognized by physicians. Isolation and lack of family involvement in patient care has serious consequences for the bereaved.

The treatment of persistent cancer is too often concerned exclusively with the disease alone, failing to see the patient as a whole. For all these patients a time will inevitably come when no further benefits are to be gained by focusing attention on new methods of curing the disease. It is at this stage that such a patient will need, above all, an awareness of himself as the person with the illness—Mr. X who happens to have terminal cancer. Dr. Cicely Saunders, Medical Director of St. Christopher's Hospice in London has not used the phrase "the terminal patient" ever since a patient objected to it saying, "it is not me who is terminal, it is my disease".

St. Christopher's Hospice in London care for people suffering from cancer or other longterm illnesses. Many of them die in the Hospice, though about 12 per cent are able to go home for awhile after their pain and other symptoms have been controlled. All these patients and their families need a much more personal sort of care than those whose illnesses can be cured, and this care must be the best that skilled nursing and medicine can provide, and must keep abreast of every modern development. It is not only the patients who are in need of help. Chronic illness, a death in the family, have wide repercussions; it is the whole family not just the patient that must be the unit of care.

The major goals of Hospice in New Haven are to:

1. Provide physical and psychological care for the patient suffering from an illness diagnosed as terminal.
2. Care for the families of dying patients during illness and bereavement.
3. Provide a support system to help people live effectively in the face of impending death.
4. Be a center for the teaching and the study of the care of the terminally ill in the United States.
5. To provide better care at less cost than present health care services.

The emphasis of the Home Care Program is to provide advanced cancer patients with a physician's care, specialized nursing services, and other forms of professional care at home, thereby extending the period of time in which patients can be safely, comfortably, and inexpensively cared for outside of the hospital or other inpatient facility. These services assist the patient to realize his fullest capacity by meeting his physical, emotional, social, and spiritual needs, thus helping patients to accept their strengths and weaknesses and allowing them to live with dignity until death.

The care of dying patients or terminal care as it has come to be called is not new, and all those who work with dying people are anxious that what is known already should be developed and extended—that terminal care should become excellent through whichever system it is delivered. There are, however, certain characteristics of a terminal care program that are deemed essential before the term "hospice" can be used to describe it. A hospice program is not just a program that proports to care for the terminally ill. It is a system of health care delivery with clearly identifiable elements. These are:

a) Coordinated home care-inpatient beds under a central autonomous hospice administration.
b) Physician directed services.
c) Control of symptoms (physical, sociological, psychological, spiritual).
d) Provision of care by an interdisciplinary team.
e) Services available on a 24-hour-a-day 7-day-a-week on-call basis with emphasis on availability of medical and nursing skills.
f) Patient/family regarded as the unit of care.
g) Bereavement follow-up.
h) Utilization of volunteers as an integral part of the interdisciplinary team.
i) Structured staff support and communication systems.
j) Patients should be accepted to the program on the basis of health needs, not ability to pay.

Physician Directed Services

Terminal patients and their families consistently report their feelings of medical abandonment. Only the other day, one of our new patients said sadly when talking to one of our staff "Well, I feel as though I have lost Dr. Q somewhere along the way." There is a time in a patient's illness when the health care professionals begin to feel that there is nothing more that they can do, and it is the loss of the interest of their doctor that patients fear the most. When a patient elects to remain home for his last weeks, this decision frequently cuts him off from effective medical care because many physicians do not make home visits. We see many patients seriously ill, suffering from vomiting, pain, and other controllable symptoms, bedfast at home, who have not seen a doctor for many weeks. Others find that if they do struggle to the office or to a hospital clinic, they frequently see a resident while the person they regard as their doctor is seeing patients who can be cured. It is vital to the psychological well-being of the patient with terminal illness that the physician is a key figure in the care he receives. This is not only psychologically important, it is also essential to his physical well-being.

Symptom Control

There is far too much talk in death and dying circles in this country about psychological and emotional problems, and far too little about making the patient comfortable. Any group concerned with service to the dying should be talking about smoothing sheets, rubbing bottoms, relieving constipation, and sitting up at night. Counselling a person who is lying in a wet bed is ineffective. Such concerns loom large in the lives of terminal patients and must be of importance to the physician if he is to treat the whole person. A certain amount of interdisciplinary role blurring may be necessary to ensure patient comfort at all times.

If people are cared for with common sense and basic professional skills, with detailed attention to self-evident problems and physical needs, then patients and families themselves cope with many of their emotional crises. Without pain, well nursed, with bowels controlled, mouth clean, and a caring friend available, the psychological problems fall into manageable perspective.

Any physician who is dealing with a number of terminally ill patients must become interested in symptoms control and skilled in the management of the various types of physical distress caused by an incurable illness. Sadly, the terminal stage has been defined by some as beginning at the moment when the doctor says "there is nothing more to be done" and then begins to withdraw subtly from the patient. Patients, of course, are very well aware when this happens. There is never a time when "nothing more can be done." There may indeed be nothing more that can be done to cure the disease but there are always further measures to be taken for the comfort of the patient.

Severe cancer pain can be controlled by narcotics and adjuvant drugs. The narcotic should be titrated to the patients need and used regularly to maintain pain control. Taken in regular, oral doses, a narcotic can be used for many months without a need to escalate the dose.

Every physician dealing with these patients should have a virtually inexhaustable store of remedies for all the common problems that we meet in terminal disease. We have found it useful to take a problem-oriented approach, treating each symptom almost as a disease in itself to be diagnosed and treated. Thus the patient becomes not Mr. A with incurable cancer, but Mr. A the man with the severe pain for which we can do a great deal. This enables one to approach the patient with a positive, optimistic, realistic attitude and the effect of such an approach on the patient and family may be dramatic.

Service Availability on a 24 Hour Basis

A husband who reluctantly placed his wife in a convalescent home for the last three months of her life described the kind of stress that forced her admission. He remembered, with vivid horror, the time her gastrostomy tube fell out at 3:00 a.m. and he tried to replace it according to phone instructions from an unknown emergency room physician.

W/ends

Such emergencies all too often occur at night and weekends when help is scarce. The fear and anxiety engendered by even the thought of such crises causes many families to give up home care. Provision of emergency availability of medical and nursing staff gives families and patients the security and support they need to continue.

Home Care—Inpatient Facilities

In Britain there are over 25 hospices. Each of these has their own combination of home care-inpatient facilities, and the precise way in which these components are implemented will naturally vary from location to location. On this side of the Atlantic there are several innovative approaches to the provisions of these two components. Hospice in New Haven is following the St. Christopher's model of building a 44 bed hospital to provide a therapeutic environment uniquely qualified to back-up the Home Care program. At the Royal Victoria Hospital, Montreal, Dr. Balfour Mount has created a 14 bed Palliative Care Unit within an acute general hospital. The unit functions largely as a separate entity, with its own philosophy of care and its own relaxation of many of the rules and regulations of the hospital. St. Luke's Hospital in New York has taken yet another approach. They provide an interdisciplinary hospice team which attends the terminal patients in the hospital wherever they may be located. Special provisions are made for hospice patients in terms of family visiting, children visiting, hair washing and the like. The team works closely with the ward staff to provide optimal care for the patient and follows the patient and family into the home setting.

Provision of Care by an Interdisciplinary Team

plan

The management of the dying must be a team concern. The team includes the dying patient, his immediate family, his doctor, the chaplain, the nurses, the social worker, the volunteers, and other health care staff. Continuity of management forms an important part of the total care. Interdisciplinary care must not be a synonym for fragmented care in which the bewildered patient does not know who is in charge or who is dealing with which problem. Real team work mandates that interdisciplinary staff sit down together at regular conferences to work out a plan of care for the patient/family and to learn each others languages.

Patient and Family Regarded as the Unit of Care

"Nothing that we do should serve to separate someone who is dying from his family. There may be moments of difficulty or even despair but it is of paramount importance that they come through to the end together. The journey itself may ease the next stages for those who have to go on living afterwards," according to Dr. Saunders. A terminal illness is not like an acute illness In an acute illness, although the short term stress may be great, the long term hope and anticipation is that full family function will be restored and life will go on as it did before. In a terminal illness every member of the family is pulled in and affected by the illness. Adjustments to living without the patient begin before death, as functions previously fulfilled by the patient have to be taken over by other members of the family. We must aim to involve the family from the beginning.

Upon admission to an inpatient facility, the family who has been nursing the patient at home has invaluable experience and advice to offer the professionals on the precise details of care; which is the most comfortable position, how frequently medication needs to be given to keep the pain under control, certain expressions unique to this particular patient. For example, a 19 year old boy was labeled confused and heavily sedated after he had repeatedly cried out in a terrified fashion that a big red engine was in the room. It was only after his death that the family told how it was the fire service who brought his oxygen to the home when he had breathing difficulties. He was trying to communicate to the hospital staff a need for oxygen and help in breathing. He was not asking to be sedated.

Time spent listening sympathetically to a husband telling of his fears for his own health because he has been passing blood in his urine for two months is well spent. Many family members deny their own needs because of the demands of looking after the sick person. However, their own needs still exist, they worry about them, and eventually they feel neglected, and may resent the patient for drawing attention away from themselves.

Over and over again we hear our families say "We could not have done it without you." One daughter told us that the hospice staff were her "backbone". "You held me up so that my hands were free to care for my father" she said. Families can manage for a much longer period of time if they have professional support immediately available to them.

Bereavement Follow-up

A hospice program provides emotional support for the surviving families during bereavement. Care does not stop with the death of the patient. We continue to visit the family on a scheduled or emergency basis, right through the death and on into the mourning period. Families require assistance as they endure the psychological suffering caused by the separation. In the first year after bereavement there is an increased vulnerability to illness reflected in a 40 per cent increase in the mortality rate of widows. Other consequences include increased alcoholism, reactive depression, and long term detrimental effects to children caused by loss of a parent. Dr. Colin Murray Parkes believes that simple friendly visiting to give the survivors an opportunity to express their grief and discuss the terminal illness and death can go a long way toward mitigating these ill effects of bereavement. St. Christopher's bereavement program makes heavy use of volunteers during this period. In Hospice in New Haven the first bereavement visits are made by the primary nurse who was involved with the care of the patient before death. This gives the family an opportuunity to discuss questions such as "Should we have kept him at home, should we have taken him to the hospital, was it worth continuing with that unpleasant treatment for so long, should we have pressed him to continue with chemotherapy, why didn't she go to the doctor as soon as she felt the lump?" Many of these questions can easily be cleared up by frank and open discussion. Left unattended they grow and fester in the minds of the bereaved to cause much unnecessary suffering.

Volunteers—Used as an Integral Part of the Home Care Team

Lay volunteers can be used to help the family with day to day tasks of running a household. The family member may be pulled away from these tasks by the demands of caring for the patient and it is the volunteer who can provide help with housework, shopping, or babysitting. They can help with laundry, patient transportation to outpatient clinics and many other apparently small but essential jobs.

The volunteer is also uniquely able to help the patient maintain or re-establish his sense of self-worth. The dependency and lack of independent functioning created by a disability eats away at a person's self esteem. The withdrawal of health care professionals as they try to cope with their own feelings of inadequacy, reinforces the patient's diminishing sense of personhood. The volunteer by forming a close friendly relationship can counteract this demeaning process. We give our volunteers basic orientation to the program but do not attempt to turn them into "counselors" for the dying. Their special value is as a person with whom the patient can identify. He sees them as "people like myself." He discusses many areas with the lay volunteer which he does not discuss with the professionals either because he feels his concerns are too silly to bother the doctor with, because he does not feel the doctor has time to attend to these concerns or because he believes the doctor would not understand his position. For one of our low income families, the volunteer who takes the patient fishing is the only person who is able at this time to provide any meaningful aid. Doctors, nurses, social workers, psychiatric services have all been employed in attempts to help him and his family deal with their multiple problems. All have been consistently rejected. The only person who is accepted and is helpful is the man who takes him fishing and in the course of those trips discusses, at the same level, on a person to person basis, the philosophies and fears this man is encountering. It is important to meet the patient on his own ground.

Terminal illness should not be regarded as intrusion into life. It is part of life and can be a time of growth for all concerned. Doctors must learn to cope with patients as human beings rather than as disease entities. They must learn not to be afraid to become emotionally involved with their patients. If they are unable to do this by reasons of personality or pressure of other work, then it is their responsibility to provide direction to other personnel who can give the patient a chance to express himself. One patient asked about her hopes for the future and said "I want to die while I'm still alive, if you know what I mean." It is our job as doctors to help it be so.

Patients Accepted on Basis of Health Needs, Not Ability to Pay

Patients are accepted on the basis of health-care need, not on ability to pay. No British hospice discriminates against patients because of their financial status, and American hospices must also strive to uphold this high standard of care. We cannot avoid our responsibility in this area by reference to socialized medicine. Most of the hospices in Britain are not under the National Health Service. They are financed by a combination of charitable donations, patient contributions, and government reimbursement.

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Comments from JHC on

HOSPICE CARE UNIT PROJECT

From Mr R. Jackson, Melbourne City Mission

1) The implication that there are no hospice facilities in Melbourne at present seems to overlook the excellent work done by Caritas Cristi, and similar work done to a lesser degree by some of the other geriatric care units. I am not really familiar with these, and if others in the ACCV are as ignorant as me, perhaps some site visiting should be arranged.

2) The 10-bed Hospitce Unit planned to cope with 30 patients, is really a bit idealistic as described in the document. Granted that medical care generally, and of this type in particular, is best managed on a teamwork basis, it is still naive to suggest that it is practical to have such a large staff for only 10 beds. If it is claimed that this is justified on the grounds that it is only a demostration unit, then it must be appreciated that it is quite un-realistic as a model that's meant to be duplicated around the country in a regional distribution.

3) I noticed that the Project Committee includes no medical oncologist, no representative from the PMH Domiciliary Care Nurses and ? no general physician. These omissions are serious in my view.

4) Although the preamble of the document emphasises the theme that many patients "want to die at home", the document provides far more discussion on "in patient care" and really deals very little with measures that enable patients who wish to die at home to in fact do so,

5) It would be worth asking Mr Jackson to define "unit of care" which he uses on a number of occasions, as I think that there is potential confusion in the way it is used in the document. The overemphasis on the fact that the family as well as the patient needs to be considered borders on sounding patronising to the family - on whom the success of a "dying at home" programme is very dependent.

6) Finally, a word of praise for the excellent paper by Sylvia Lack, which is attached to the document. This is so good that it should be essential reading for all members of our Terminal Cancer Management Committee and in fact for all oncologists.