THE CARE OF THE TERMINALLY ILL

The report of the working group of the
Wellington Health Services Advisory Committee

December 1981
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WELLINGTON HEALTH SERVICES ADVISORY COMMITTEE,
Education House West, 178-182 Willis Street,
Wellington, New Zealand.
FOREWORD

It has been a pleasure to chair the Working Group on the Care of the Terminally Ill. The report which follows is the result of eight months work and I would pay tribute to all the members. The Working Group was a multi-disciplinary one and its work was marked by a degree of openness and tolerance which was unique. Some members had had recent experience of bereavement and grief and they were able to make a special contribution.

The Working Group was keen to see this report followed up and made a reality. To this end they suggested that the Wellington Division of the Cancer Society of New Zealand should sponsor an advisory group on terminal illness which would ensure that these recommendations were not forgotten.

The Wellington Health Services Advisory Committee carefully considered the full report and decided that they would sponsor a monitoring group. It is my hope that the group will in due course elect its own chairman. I believe this report could set the pattern for each major region in New Zealand and certainly the financial recommendations in the report will need to be considered nationally.

CALEB TUCKER
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1.0 PREFACE

In November 1980, Mr Caleb Tucker, Superintendent-in-chief of the Wellington Hospital Board, wrote to Mr Spencer Russell, Chairman of the Wellington Health Services Advisory Committee (WHSAC), enquiring whether a working party on "the care of the terminally ill" could be established under the auspices of this Committee.

The initiative for the working party arose from a report prepared by the Department of Radiotherapy and Oncology of Wellington Hospital, and the Corporate Planning Unit of the Wellington Hospital Board (Ref.6). The report suggested there was a need for a regional policy on the care of the terminally ill. The findings were supported by the Wellington Division of the Cancer Society of New Zealand.

In response to the report, Mr Tucker convened a meeting representative of people concerned with the terminally ill in the Wellington region, Appendix I.

After two meetings a working group was established to consider:

(A) The need in the Wellington area to develop a comprehensive regional policy for the care of the terminally ill, which ultimately could have government endorsement.

(B) The need for financial support for hospices.

In December 1980 WHSAC requested and received ministerial approval of the terms of reference and membership of the Working Group. The first meeting of the group was held on 10 March 1981.

1.1 MEMBERSHIP OF THE WORKING GROUP

Mr C.L. Tucker (Chairman) Medical Superintendent-in-Chief, Wellington Hospital Board; member of WHSAC.

Dr J.D. Bonifant General Practitioner, Karori Medical Centre; Associate Member, Royal New Zealand College of General Practitioners; member of Mental Health Shadow Service Development Group (SSDG).

Mrs M.D. Cooper Director, Community Domiciliary Nursing Trust; member of Primary Health Care SSDG; member of WHSAC.

Ms L.C.T. Dyall Advisory Officer, WHSAC.

Mr H.R. Evans Chairman, Wellington Division of the Cancer Society of New Zealand.
2.0 TERMS OF REFERENCE

(A) Define the term "terminally ill patient".

(B) Describe the physical, emotional, spiritual, financial, domestic, and social problems encountered by the terminally ill patient and his family in the Wellington region.
Describe the strengths and weaknesses of the relevant programmes of the existing statutory and voluntary agencies involved in the care of the terminally ill patient and his family in the Wellington region.

Present to WHSAC a co-ordinated plan for total care of the terminally ill patient and his family within the Wellington region, including the methods of funding.

3.0 DEFINITION OF TERMINAL ILLNESS

While any progressive disease is a terminal illness, there is, within the period of the disease, a terminal stage during which the patient could require special services. It was considered essential that the definition include a specific time period, which should not be excessively long, and it was agreed that this should be twelve months.

The following is the definition accepted:

"A TERMINAL ILLNESS IS ANY PROGRESSIVE ILLNESS FROM WHICH THE PATIENT IS EXPECTED TO DIE, AND IN WHICH THERE IS NO FURTHER PROSPECT OF CURATIVE TREATMENT.

A TERMINALLY ILL PERSON IS ONE WHO SUFFERS FROM A TERMINAL ILLNESS, AND WHOSE LIFE EXPECTANCY WOULD NORMALLY BE LESS THAN TWELVE MONTHS, DURING WHICH TIME ACCESS TO SPECIAL SERVICES MAY BE REQUIRED".

4.0 DEMOGRAPHIC DATA

At the request of the Working Group, a study entitled "Terminal Illness in Wellington" was carried out in May and June 1981 by a group of fifth year medical students as part of the one month course on Community Health at the Wellington Clinical School of Medicine (University of Otago) (Ref.7). The study was supervised by Professor K.W. Newell. Using the definition above, the students perceived that in order to be classified as terminally ill, persons must fulfil three criteria:

1. They must be suffering from a progressive illness.
2. There must be little possibility of curative treatment.
3. They must be expected to die within the next twelve months.

The objective of this research was to supply the Working Group with data such as:

1. How many people were terminally ill in a year?
2. What are some of their qualities? (e.g. age, sex, diagnostic category, location).
3. Which services did they use?
4. Who provided support and advice?
The study group examined half of the Wellington Health District death certificates for 1980, and tried to determine how many had died following a terminal illness. This gave information concerning the incidence, sex, diseases, and residence of the deceased.

Some difficulty was found in applying the definition of terminal illness retrospectively to some illnesses other than cancer.

The second part of the study consisted of twenty-four interviews with relatives of those who had died after a terminal illness. The findings gave some insight into the provision and use of services by the terminally ill, but the smallness of the sample prevented the findings being extrapolated to the terminally ill in general.

The main findings of this study in the Wellington Hospital Board area are:

1. In 1980 it was estimated that there were between 539 and 872 deaths from terminal illness.
2. Prevalence rate of terminal illness at any one time was estimated to be approximately 600.
3. The interval between recognition of a terminal illness and death was approximately 44 to 47 weeks.
4. A third of all deaths from terminal illnesses were people aged under 65 years.
5. Illnesses that were ultimately defined as terminal usually lasted longer than 12 months.
6. 50% of all such deaths were due to cancer.
7. 25% of all such deaths were due to cardiac disease.
8. 41% lived in Upper and Lower Hutt, and 36% lived in the Wellington City area.
9. 45% died in a public hospital.
10. 23% died at home.
11. 28% died in a hospice.
12. 3.5% died in a private hospital.
13. 32 contacts with the various services providing care for the terminally ill left an impression of very satisfactory to excellent standards of health care.
14. The most commonly used service was the Community Health Nursing Service of the Wellington Hospital Board.

The full report is included as Appendix II.

5.0 DESCRIPTION OF PHYSICAL, EMOTIONAL, SPIRITUAL, FINANCIAL, AND DOMESTIC PROBLEMS ENCOUNTERED BY THE TERMINALLY ILL PATIENT AND HIS FAMILY

Although many of the above problems overlap, each was considered under individual headings. The full report is included as Appendix III.

In summary, it was found that:

1. Physical problems are very common, often severe, and frequently poorly controlled for long periods of time.
2. Fear is common in terminal illness.

3. Existing services have the potential for preventing problems, whether physical, spiritual, financial, emotional, or domestic, but in a real life situation they may fail to do so.

4. Many problems could have been prevented by early identification in individual cases, or by better communication between services.

5. There are not sufficient data available to quantify the problems for the whole of the terminally ill population.


The sub-committee which investigated this area identified statutory, voluntary, and private agencies which were likely to provide services for the terminally ill, and asked them a series of questions as listed in Appendix IV.

6.1 STATUTORY AGENCIES

Statutory services for the terminally ill in the region are provided primarily by two agencies (Department of Social Welfare and the Wellington Hospital Board).

1. Department of Social Welfare

The terminally ill are assessed as to whether they meet the criteria of eligibility for the general range of financial benefits and social services provided through the Department. No benefits are designed specifically for the terminally ill. See Appendix V.

2. The Wellington Hospital Board

The Wellington Hospital Board provides a wide range of services for the terminally ill, with increasing consideration being given to the specific needs of this group. In-patient, out-patient, and home care are provided, and medical, nursing, paramedical, chaplaincy and home support services are available. A list of these services is included in Appendix VI.
6.2 VOLUNTARY AGENCIES

The majority of agencies approached does not appear to have a formal policy for the care of the terminally ill, although most of the agencies would be prepared to help terminally ill patients and their families. The ability of many agencies to assist was limited. Generally, it was found that there was a lack of knowledge of the services available. The agencies approached fall into two broad groups:

1. Those that are organised to give active support. For example:

   The Wellington Division of the Cancer Society of New Zealand
   Mary Potter Hospice
   Te Omanga Hospice
   The Community Domiciliary Nursing Trust
   Home of Compassion
   Little Sisters of the Assumption, Home nursing and patient centre
   Russell Kemp Hospital
   Salvation Army
   Wesleyhaven Eventide Homes
   Woburn Home

2. Those that would be willing to assist but are restricted in what they can do by the nature of their aims, objectives, and structure. For example:

   Bereaved Parents' Association
   Citizens' Advice Bureaux
   New Zealand Returned Services Association
   New Zealand Widows' and Widowers' Association

For a full report on the services provided by these agencies see Appendix VII.

6.3 PRIVATE SECTOR

The role of the general practitioner in the care of the terminally ill is of paramount importance. It is the responsibility of the general practitioner to ensure that a satisfactory standard of medical care is provided for terminally ill patients and their families. General practitioners who are unable to provide terminal care should refer patients and their families to the appropriate services. For a description of the role of the general practitioner see Appendix VIII.
In summary, it was found that:

1. The services available are capable of providing good care for the terminally ill in the Wellington region, but could be improved by:
   (a) Developing existing services;
   (b) Educating the general public and health professionals.

2. Most of the services are available through the Community Health Nursing Service, hospitals, hospices and general practitioners.

3. There is a general lack of knowledge in the community as to the services available for the terminally ill. Improved methods for disseminating this information need to be established.

4. With the exception of the two hospices and the Wellington Division of the Cancer Society of New Zealand, the voluntary agencies interviewed do not provide a service specifically designed for the terminally ill.

7.0 THE DEVELOPMENT OF SERVICES AVAILABLE FOR THE CARE OF PATIENTS TERMINALLY ILL WITH CANCER

Since 1968 a number of services financed by public, private and voluntary organisations have been developed for the care of the terminally ill cancer patients in the Wellington region.

7.1 HISTORICAL DEVELOPMENTS

1. 1968 - Introduction of night nurses for the care of patients at home by the Community Domiciliary Nursing Trust, funded by the Wellington Division of the Cancer Society of New Zealand.

2. 1975 - The Mary Potter Ward, Calvary Hospital, set aside five beds for the care of terminally ill cancer patients. From this developed the Mary Potter Hospice of 23 beds, which was officially opened in 1979.

3. 1976 - The first Specialist Oncology Nurse appointed by the Wellington Hospital Board. Currently, three nurses are employed by the Community Health Nursing Service, and for a limited period part of their funding was provided by the Wellington Division of the Cancer Society of New Zealand.

4. 1978 - "Cancer phone service" provided for the public by Community Health Nursing Service, and funded by the Wellington Division of the Cancer Society of New Zealand.

5. 1979 - Opening of Te Omanga Hospice, a community-based hospice programme in Lower Hutt.
7.2 DESCRIPTION OF CURRENT SERVICES

The services which have evolved in the Wellington Hospital Board area include a home care programme provided by the Community Health Nursing Service. It is linked to the general practitioner, three acute general hospitals, and two voluntary hospices. No formal structural organisation exists, but the following is a description of how the services operate:

Patients are identified and referred to the Community Health Nursing Service by ward charge nurses, hospital medical staff, hospices, general practitioners, and by the public via the "cancer phone".

The Community Health Nursing Service employs three oncology nurses whose sole responsibility is to care for cancer patients in the community, particularly those whose illnesses are terminal. They support and counsel the patient and family, and provide nursing care in co-operation with local district nurses, and liaise with general practitioners, hospitals, and hospices as appropriate.

A. Community care

The patient in the community is under the care of his general practitioner, who is notified by letter when the patient is discharged from hospital. In the Hutt Valley such care may be taken over by the Te Omanga Hospice team if the general practitioner wishes.

Cancer patients are visited by an oncology nurse, who then communicates with the general practitioner as necessary. The oncology nurse may be considered a link between hospital-based medical care and that of the general practitioner, who, together with his practice nurse, may choose to take over much of the role of the oncology nurse. Home care is facilitated by regular visits by district nurses, who are often in close contact with the oncology nurse.

Night nurses can be arranged by the district nurse, oncology nurse or the general practitioner. Patients requiring re-admission will be admitted to a public or private hospital or hospice, as the patient, general practitioner, and oncology nurse decide. The oncology nurse will carry out bereavement visits to the surviving family, as may the general practitioner.

B. Hospice care

The move towards hospice care has been stimulated by two main factors:

1. An increased awareness that traditional health care is often inadequate for the special needs of the dying.
2. The high level of pain and other distressing symptoms often associated with terminal illness. In a retrospective study, C.M. Parkes of St. Christopher's Hospice, London, documented the pain experienced by patients with terminal cancer. He found that 28% of those cared for at home, 20% of those in general hospitals, and 8% of those in hospices suffered severe and unrelieved pain (Ref. 8).

A hospice is a programme of co-ordinated in- and out-patient services primarily concerned with maintaining the patient at home, but providing back-up in-patient services when necessary. Total patient care includes caring for the family and other significant patient relationships. Regulations are kept to a minimum. There is extensive co-operation with other services.

Hospices avoid the high technology approach to medicine of general hospitals, and concentrate on maintaining the patient's quality of life at the highest possible level. Pain relief and support of the patient and relatives are more effectively dealt with by the application of hospice concepts. Hospices are not seen as an alternative to home care, but as extending and complementing the total care of terminally ill patients in the community. So far their development has generally taken place outside the Government Health Service. They act as resource centres with special skills and expertise in the care of the dying, and will continue to do so until such time as these concepts and skills gradually become part of general medical and nursing practice, influencing the care of all patients.

There are two hospices in the Wellington region. See Appendix XII for a description of the Mary Potter Hospice in Wellington, and Appendix XIII for the Te Omanga Hospice in Lower Hutt (Refs. 4 and 10).

**DESCRIPTION OF REQUIREMENTS FOR GOOD TERMINAL CARE FACILITIES**

Any programme of care should:

1. Consider the patient and family group as the unit of care.

2. Be available to the patient wherever he may be.

3. Deal effectively with patient and family group problems of all types.

4. Provide continuity of care 24 hours a day.

5. Be delivered by an integrated team of professionals committed to this area of care.

6. Be free to patient.

7. Provide staff support.
8. Be actively involved in education, i.e. in-service training for health professionals, and promotion of community awareness.

9. Be actively involved in research.

In summary, it was found that:

There is a wide range of facilities for terminally ill patients in the Wellington region, and while statutory agencies cope with the majority of patients, recent years have seen the growing involvement of voluntary agencies. The Wellington Division of the Cancer Society of New Zealand, and the two hospices supplement the home care service provided by the Community Health Nurses and general practitioners, improving the overall quality of care. The organisation that exists is, for the most part, voluntary and flexible, rather than regimented.

8.0 PROBLEMS ENCOUNTERED IN THE PRESENT SYSTEM

Deficiencies have been identified in the following areas:

8.1 PATIENT IDENTIFICATION

All terminally ill patients will have received medical attention, either in a hospital or from their general practitioner, but not all will receive adequate supportive care during their illness.

Patients and their families are often unaware of the services available to provide help with the emotional, physical, social, financial or spiritual problems that may arise. There may also be a delay in providing appropriate services such as spiritual advice, nursing help or financial assistance. For a full description of the problems, see Appendix III.

The general conclusion of the sub-committee investigating this area was that many problems could be prevented by early recognition of a particular need, by either the patient, family or health professional.

8.2 ROLE OF THE FAMILY

Many consider the ideal place to care for a terminal illness is at home. Families who undertake the responsibility of caring for a dying relative generally find comfort and satisfaction in this role.

Health professionals may not recognise the stress which is placed upon members of a family caring for a patient at home, and, at the same time, trying to cope with their own emotions. The care given by a family is often relieved only by intermittent visits from community health nurses, the general practitioner, or spiritual advisor.
When taking on the commitment of caring for a dying relative, families should be advised that they can request assistance such as home help or intermittent relief from caring for the patient. Health professionals visiting the home regularly should monitor patient needs continuously, and make on-going assessments as to whether a family could benefit from a particular service.

8.3 ROLE OF COMMUNITY HEALTH NURSES IN THE CARE OF THE TERMINALLY ILL

Excellence in terminal care begins with high standards of nursing and medical care. Supportive care of patients at home is centered on community health nurses, while coordination of medical care is the responsibility of the general practitioner. The care of the patient and family is a team effort, with nurses providing continuity of care and support in association with the doctor. Their roles are complementary. Unless the central role and responsibility of the nurse is appreciated by the doctor, this can be an area of conflict.

8.4 ROLE OF THE DOCTOR IN THE CARE OF THE TERMINALLY ILL

There is, on the part of doctors, a general lack of knowledge of the therapeutic possibilities in treating the terminally ill, often associated with an inability to deal comfortably with a dying person. This may inhibit a constructive patient and doctor relationship, both in hospital and in the community. There are many technical problems which the doctor is well placed to deal with, pain and symptom control in particular (Ref.9). The doctor should be aware of the range of services available to the patient and how best these can be organised. Possible reasons for the lack of medical care during a terminal illness are:

(a) Lack of skill on the part of the doctor;
(b) Unwillingness by the doctor to be involved;
(c) The doctor is denied the opportunity to be involved.

8.5 TRAINING AND EDUCATION

Health professionals generally have great difficulty informing a terminally ill patient and his family of the diagnosis and prognosis. Nurses and doctors receive little training to help them cope with their own reactions to death, let alone provide the support and counselling a dying patient and his family will require.
Health professionals' lack of skills in the care of the terminally ill causes many problems. For example, a doctor may avoid contact with a terminally ill patient in order to protect his own feelings. Health professionals need to face the problems of dying patients, and to be equipped with the skills to deal with their problems, particularly pain and symptom control. They can provide access to services and help the patient decide what type of care is appropriate. The health professional should aim to improve the quality of daily life of the terminally ill patient.

8.6 COMMUNICATION

Conflict in the team approach to terminal care can develop because:

1. There is lack of agreement as to goals and purposes.
2. The role of each team member is not clearly defined.
3. There may be inadequate channels of communication amongst members of the team or organisations.

Communication is often lacking because:

1. The patient may be unaware of the nature of his illness and prognosis, which may hinder the provision of appropriate services.
2. Once discharged from hospital, many patients are not aware that they are now under the care of their general practitioner, even though they may still be seeing a hospital specialist.
3. Communication between hospitals and general practitioners is usually by letter. This may be ineffective in initiating action.
4. Hospital letters may arrive some time after the patient has been discharged, and though they provide information about diagnosis and treatment, they may not indicate the degree of the patient's understanding of the illness, or what further action is intended.
5. It is difficult for a general practitioner to initiate a visit to a patient without the patient requesting it.

8.7 HOSPICE CARE

There can be a problem in providing care of a uniform quality to terminally ill patients, whether they are in hospital, a hospice or at home. The variation in the standard of care throughout the region has resulted in the development of the two hospices to complement the home care service. Their aim is to ensure that the patient's quality of life, both physically and mentally, will be sustained at the highest possible level. To achieve this, hospices can concentrate relevant disciplines to a greater degree than can be achieved in the home or in hospital, though hospice-type care can be applied in any setting by the proper organisation of currently available services (Refs. 4 and 10).
A. EXPLANATION OF TERMS

1. Private hospital daily patient bed benefits

This is a benefit paid under section 102 of the Social Security Act 1964 to patients in private hospitals. There are five categories of payment:

- Geriatric (patient 65 years and over)
- Medical (under 65 years)
- Long-term (under 65 but in hospital 90 days and over)
- Surgical
- Maternity

A hospice would need to be licensed as a private hospital for patients to attract payment of the appropriate benefit.

2. Geriatric Hospital Special Assistance Scheme

Under this scheme, a patient is assessed by the regional geriatric physician or an authorized medical practitioner for subsidised care in a private hospital when an appropriate public hospital bed is not available.

The patient contributes all income, less $5 per week, for his or her personal use. The difference between the patient's contribution and the cost of the bed is made up by the Daily Bed Benefit, and a subsidy is paid by the Hospital Board under the Geriatric Hospital Special Assistance Scheme. Russell Kemp Hospital would be an example of how fees are met:

- Weekly private hospital charge, say $300.50
- Patient income (say National Superannuation less $5.00) 77.00
- Daily Geriatric Bed benefit ($21.50 x 7 days) 150.50
- Geriatric Hospital Special Assistance Scheme 73.50
- $300.50

3. Income test

The patient must declare all income. An assessment is made as to whether the patient is entitled to a full benefit or assistance under the Geriatric Hospital Special Assistance Scheme. An exception is made in the case of married couples. Where one spouse is hospitalised, either in a public or private hospital, National Superannuation is paid in full to the spouse at home.
4. Asset test

Assessment for monetary assistance is based on income and assets. For example, a pre-condition as to whether an individual may receive a subsidy under the Outdoor Relief Scheme is that assets amount to no more than $900.

B. EXISTING PAYMENTS FOR HOSPICE CARE

Payment for hospice care from public funds is made in the following circumstances:

1. If 65 years or over:
   (a) Geriatric bed benefit of $21.50 per day applies.
       (On 1.12.81 this will increase to $23.50).
   (b) Assistance may also be given under the Geriatric Hospital Special Assistance Scheme provided the patient is first assessed by the geriatric physician or his appointee as requiring hospital care.

       A private fee-paying patient would not be eligible for the subsidy, although he or she would receive the patient benefit as in (a) above.

2. If the patient is under 65 years of age:
   (a) Patients occupying hospice beds are eligible for the Medical Benefit, which at present is $19.00 per day for short stay patients. If the patient is termed long-stay a benefit of $21.50 applies.
       (On 1.12.81 these will increase to $20.50 and $23.50 per day respectively).
   (b) For patients being nursed in their own homes, the Department of Social Welfare provides benefits such as the Sickness Benefit, Invalids' and Miners' Benefit, Domestic Purposes Benefit for Care at Home of the Sick or Infirm, and Disability Allowance. All are income tested.

       Comment: there is no specific financial assistance designed for the terminally ill.

3. There is a need for a higher nurse-to-patient ratio in a hospice than in a geriatric unit. There is more heavy nursing in a hospice as well as increased time involvement owing to the counselling needs of both patient and family.
A study at the Mary Potter Hospice, which has 23 beds, showed the following differences between it and a geriatric unit of similar size, see Appendix XI.

**ADDITIONAL STAFF REQUIRED AT MARY POTTER HOSPICE**

<table>
<thead>
<tr>
<th>Time of Day</th>
<th>Extra Staff Required</th>
</tr>
</thead>
<tbody>
<tr>
<td>Morning shift</td>
<td>1 extra Little Company of Mary Sister</td>
</tr>
<tr>
<td></td>
<td>1 extra Registered Nurse</td>
</tr>
<tr>
<td></td>
<td>1 extra Hospital Aide</td>
</tr>
<tr>
<td>Afternoon shift</td>
<td>0.5 extra Registered Nurse</td>
</tr>
<tr>
<td>Evening shift</td>
<td>1 extra Registered Nurse</td>
</tr>
</tbody>
</table>

Difference in salary costs per annum = $72,930

Current as at 31 March 1981.

8.9 IMPLEMENTATIONS OF RECOMMENDATIONS

Care of the terminally ill covers many facets of nursing, medical, paramedical and supportive care. It requires some mechanism which will co-ordinate public, private and voluntary services. This should be advisory rather than executive, and it should include all the main groups concerned.

Our objective as a Working Group is to ensure that every dying patient has access to professional staff or lay people who can provide appropriate care. It is to this end that we advise the formation of an "Advisory Group" for the care of the terminally ill.

The formation of an advisory group on terminal illness in the Wellington region should be a continuing body including representatives of the Wellington Hospital Board, the two hospices, specialists in terminal care and oncology both nursing and medical; and other supportive groups.
RECOMMENDATIONS

9.0

PATIENT IDENTIFICATION

9.1

(a) THAT: The Wellington Division of the Cancer Society of New Zealand produce a pamphlet listing available services for the terminally ill. This should be circulated to the following people and organisations in the Wellington region:

(i) Patients and the public, through doctors' waiting rooms, hospital departments and other public services as appropriate;

(ii) All doctors;

(iii) All community health nurses;

(iv) All ward charge nurses in public and private hospitals;

(v) All branches of the Citizens' Advice Bureaux;

(vi) All religious organisations and parishes of all denominations.

(b) The pamphlet to be re-issued yearly, and its contents to be revised two yearly. The Wellington Division of the Cancer Society of New Zealand to be responsible for distribution and posting of the pamphlets.

(c) The Wellington Division of the Cancer Society of New Zealand continue to support and advertise its "cancer phone".

(d) Hospital patients with a terminal illness be referred to the Community Health Nursing Service before discharge. There is a need to improve communication between ward charge nurses and community health nurses. This could be facilitated by community health nurses frequently visiting hospital wards.

(e) Terminally ill patients leaving hospital have a "planned discharge". This should include notifying the patient's general practitioner prior to discharge so that the appropriate community services are arranged. Some patients and their families should have a trial of home care before finally being discharged from hospital. If any problems develop the patient could be rapidly re-admitted.
(f) All doctors be encouraged to refer patients with problems related to their terminal illness, to the services provided by the two hospices, or, for cancer patients only, to the clinics run by the Department of Radiotherapy and Oncology at Wellington, Hutt, and Kenepuru hospitals.

9.2 THE PATIENT AND FAMILY

When circumstances allow, the most suitable place to care for terminally ill patients is in their own homes. The provision of all supportive services should be arranged.

(a) THAT: Terminally ill patients at home, and their families have the services of their general practitioner and community health nurse, who will be jointly responsible for their care.

(b) All patients and their families should have the right to be fully informed of the diagnosis and prognosis, if and when they so request, by a medically qualified person, preferably their general practitioner or medical specialist. In some circumstances a suitably qualified nurse may be the appropriate person to inform the patient and family.

(c) Patients at home be continually assessed by the general practitioner and community health nurse as to the need for further supportive services such as intermittent in-patient care to relieve the family, for symptom relief, or the provision of spiritual advice or other services as necessary.

9.3 COMMUNITY HEALTH NURSES

(a) THAT: Community health nurses be informed of the range of services available to the terminally ill, so that they can co-ordinate these services to help patients cope with the physical, emotional, spiritual, financial, domestic and social problems of their illness.

(b) For nurses providing care for terminally ill patients and their families, allowance must be made for the stress created by this particular type of work. This should be reflected in staffing levels, and by these nurses having the opportunity to interchange with other related disciplines. Due consideration should be given to the management and prevention of work stress.
For adequate home care of terminally ill patients, sufficient nursing services need to be available. A study should be carried out to investigate the manpower and conditions of service required to provide a 24-hour continuous Community Health Nursing Service for the terminally ill at home.

9.4

THE DOCTOR

(a) THAT: Hospital specialists and general practitioners have the responsibility to inform a terminally ill patient, and with the patient's agreement, his or her family of the diagnosis and prognosis, if and when they so request. The doctor should do this personally, with honesty and sensitivity. A quiet and private place should be available, and ample time allowed for discussion between the doctor, patient and family. If the patient and family wish to have further discussions, this should be arranged as necessary.

(b) The doctor should be aware of the therapeutic possibilities in treating the terminally ill, and the range of services available. A doctor not wishing to care for a terminally ill patient is obliged to arrange care by other appropriate services, for example another doctor or a hospice service.

(c) Doctors should appreciate the central role of the community health nurse in the care of the terminally ill at home.

(d) Where a visit to a terminally ill patient is initiated by the doctor, the General Medical Services Benefit should be payable for the consultation.

(e) The general practitioner should be aware that a higher rate of benefit is available from the Department of Health for repeated visits to a patient requiring continuing care.

(f) The general practitioner should be aware that drugs not available on the Department of Health's free list need not be paid for by the patient. A brief letter to the Department explaining the need for the use of a specific drug can usually gain approval for free funding.
9.5 TRAINING AND EDUCATION

(a) THAT: Undergraduate training at the Wellington Clinical School of medicine should include a terminal care component. Education programmes should place greater emphasis on instruction in terminal care, including methods of counselling and bereavement care.

(b) Nursing education programmes should place greater emphasis on instruction in terminal care, including methods of counselling and bereavement care.

(c) An elective period in terminal care should be included in the postgraduate and continuing education courses arranged by the Royal New Zealand College of General Practitioners, the Royal Australasian College of Surgeons, and the Postgraduate Medical Society. Training in terminal care is at present included in the courses of the Royal Australasian College of Radiologists and the Royal Australasian College of Physicians.

(d) An elective period in terminal care should be included in postgraduate nursing education, especially as regards that of technical institutions.

(e) Patients and public should be regularly informed of the facilities and services available for the terminally ill.

(f) Encouragement should be given to the provision of opportunities for the public and health professionals to discuss these issues and foster a changed attitude towards terminal illness.

9.6 COMMUNICATION

On leaving hospital, patients should be informed:

(a) THAT: They are under the care of their general practitioner at all times in the community.

(b) Their general practitioner is available to assist on medical matters and is aware of their condition and treatment.

(c) The patient and family should be informed, before leaving hospital, of the range of services available. They should know how to gain access to them when needed.
The hospital consultant responsible for the patient should ensure that letters written from hospital about a terminally ill patient are sent before the patient is discharged. The letter should include extra information on the patient's prognosis, the patient's understanding of his illness and his reaction to it, and what further action is intended for the patient's care.

The ward charge nurse should be responsible for ensuring that terminally ill patients are referred to the Community Health Nursing Service when they are discharged from hospital, and that the general practitioner is notified by telephone that the patient is returning home.

9.7 HOSPICE CARE

In the Wellington region there is a mixture of public, private and voluntary organisations providing specific services for the terminally ill. These services consist of:

(i) General practitioner;
(ii) Community health nurses;
(iii) The two hospices;
(iv) The public hospital services;
(v) Ancillary and spiritual services.

The voluntary co-operation and co-ordination between these services has established a high standard of care in the region (Ref. 2, 4, 7, and 10). It is recommended that the current system be continued and supported, and expanded on the basis of the recommendations above. Co-operation amongst the various services could be enhanced by an interchange of staff, at the request of individual members.

There is a need for medical specialists in terminal care, and they should be funded through the Health Service:

(a) THAT: A terminal care specialist be appointed with responsibilities at Wellington Hospital, the Mary Potter Hospice, Kenepuru Hospital, and the Wellington Clinical School of Medicine. Duties would include forming a terminal care team* to see in-patients at Wellington and Kenepuru hospitals, and being available for consultation with general practitioners and community health nurses on patients at home (Ref. 3). He or she would work with the staff at the Mary Potter Hospice, and carry out teaching and research programmes on terminal care.
(b) A terminal care specialist be appointed with responsibilities at Hutt Hospital and Te Omanga Hospice. Duties would include forming a terminal care team* to see in-patients at Hutt Hospital, and be available for consultation with general practitioners and community health nurses on patients at home (Ref.3). He or she would work with the staff at the Te Omanga Hospice, and carry out teaching and research programmes on terminal care.

*The team here describes an identified consultative group (many of whom already exist) including a doctor, a nurse and a social worker, with access to other disciplines such as psychiatry and the clergy. Experience has shown that the terminal care specialist may come from one of a number of medical disciplines, including general practice.

(c) Further development of the West Coast, including Kenepuru, may proceed by means of a satellite team initially supported by the Wellington and Hutt teams.

(d) The availability of specialists in terminal care is universally limited. Provision of funds, and the increasing supply of doctors should, however, make such appointments feasible.

(e) The development of hospices in the Wellington region using charitable and community funds has been in response to historical problems. Hospices elsewhere will vary in form and funding, in response to local resources and population spread. Hospice beds may well be part of a public hospital, and their requirements must be properly provided for. Local community input is needed to help establish these as "special places", and maintain standards and provide flexibility.

9.8 THE DEPARTMENT OF HEALTH

(a) THAT: The care of the dying and their families should be recognised as a legitimate area of health care.

(b) The Department of Health should devise specific guidelines, both nationally and regionally, on the desirable level of facilities and services for the care of the terminally ill.
9.9  FUNDING FOR HOSPICE CARE

In considering a funding policy to meet the needs of terminally ill patients and their families the following should be considered as possibilities:

(a) **THAT**: The subsidy under the Geriatric Hospital Special Assistance Scheme be extended to all terminally ill patients, irrespective of age.

(b) A new category of bed benefit, called the "Benefit for the Terminally Ill", be introduced. The reasons for this recommendation are:

(i) The benefit should be higher than that for a geriatric patient, irrespective of the patient's age, because of the higher nursing ratio required for terminally ill patients and the associated extra costs, see Appendix XI. This benefit should be 20% higher than Geriatric Bed Benefit.

(ii) The time required for payment of the benefit would be short. It has been estimated that the average length of a terminal illness in the Wellington region is between 44-48 weeks. At the Mary Potter Hospice, short-term patients (247 in 1980-81) had an average stay of 20.21 days. Therefore the duration of payment is relatively brief in comparison with that of geriatric patients.

(c) A terminally ill benefit designed along these lines would be applicable to all patients falling within the definition of "terminally ill". See page 2, paragraph 2.1.

(d) Assessment of patients for this benefit may need to be restricted to designated medical practitioners. Alternatively, payments could be restricted to terminally ill patients in a hospice (rather than for all such patients in private hospitals), but this would require definition and registration of hospices as such. For definition of a hospice, see Appendix IX.

(e) Adequate funds be provided for the provision of 24-hour care of patients at home by community health nurses, based on national guidelines.
9.11 IMPLEMENTATION OF RECOMMENDATIONS

That an advisory group on terminal illness be formed in the Wellington region under the auspices of the Wellington Health Services Advisory Committee to advise upon ways in which the services for the terminally ill can continue to develop:

(a) THAT: Members of this group include representatives of the Wellington Hospital Board, the two hospices, specialists in terminal care and oncology both nursing and medical; and other supportive groups.

(b) The group be responsible for the follow-up of the recommendations of this report.

10.0 ORGANISATIONS TO WHOM THESE RECOMMENDATIONS SHOULD BE DIRECTED

10.1 THE WELLINGTON DIVISION OF THE CANCER SOCIETY OF NEW ZEALAND

(a) THAT: It produce and distribute a pamphlet listing available services for the terminally ill, see 9.1 (a) and (b).

(b) It continue to support and advertise the "Cancer phone", see 9.1 (c).

10.2 THE WELLINGTON HOSPITAL BOARD

(a) THAT: There is a need for patients leaving hospital to have a "planned discharge", see 9.1 (e).

(b) Medical and ward staff be informed of the range of services available to the terminally ill, and the need to inform the patient and family of these services before the patient is discharged from hospital, see 9.6 (c).
IMPLEMENTATION OF RECOMMENDATIONS

That an advisory group on terminal illness be formed in the Wellington region under the auspices of the Wellington Health Services Advisory Committee to provide advice on which of the services for the terminally ill can continue to develop.

Members of the group include representatives of the Wellington Hospital Board, the two hospices, specialists in terminal care and anaesthetics, palliative nursing, and social workers. The group is responsible for the follow-up of the recommendations of this report.

ORGANISATIONS TO WHOM THESE RECOMMENDATIONS SHOULD BE DIRECTED

10.0

THE WELLINGTON DIVISION OF THE CANCER SOCIETY OF NEW ZEALAND

10.1

As produce and distribute a pamphlet providing suitable services for the terminally ill. See 9.1 (a) and (d). (c)

If continue to support and advertise the "Cancer Phone", see 9.1 (c)....

10.2

THE WELLINGTON HOSPITAL BOARD

There is a need for patients leaving hospital to have a "Planning discharge" plan. Medico-surgical specialists are informed of the need to have a "planning discharge" plan. (a)

The need for services appropriate to the care of terminally ill patients and families of these services. (b) (d) (e) (c)
(a) **THAT:** Members of this group include representatives of the Wellington Hospital Board, the two hospices, specialists in terminal care and oncology both nursing and medical; and other supportive groups.

(b) An approach be made to the Wellington Division of the Cancer Society of New Zealand to sponsor this group and nominate an independent chairman.

(c) The group be responsible for the follow-up of the recommendations of this report.

### 10.0 ORGANISATIONS TO WHOM THESE RECOMMENDATIONS SHOULD BE DIRECTED

#### 10.1 THE WELLINGTON DIVISION OF THE CANCER SOCIETY OF NEW ZEALAND

(a) **THAT:** It sponsor the formation of an advisory group on terminal illness in the Wellington region, and to nominate an independent chairman, see 9.11 (a) (b) (c).

(b) It produce and distribute a pamphlet listing available services for the terminally ill, see 9.1 (a) and (b).

(c) It continue to support and advertise the "Cancer phone", see 9.1 (c).

#### 10.2 THE WELLINGTON HOSPITAL BOARD

(a) **THAT:** There is a need for patients leaving hospital to have a "planned discharge", see 9.1 (e).

(b) Medical and ward staff be informed of the range of services available to the terminally ill, and the need to inform the patient and family of these services before the patient is discharged from hospital, see 9.6 (c).
(f) Where hospice beds are developed in a public hospital, such beds should receive commissioning funds, on the basis of national guidelines, sufficient to maintain the quality of care in accordance with hospice concepts.

9.10 FINANCIAL ASSISTANCE

FOR THE TERMINALLY ILL PATIENT

That some form of financial assistance be available to the patient and/or family where, owing to a terminal illness, financial hardship is encountered. This applies particularly where a member of a family ceases work to nurse a terminally ill relative in a home situation.

(a) THAT: This assistance should be income tested and not "asset tested".

It must be realised that with nearly 50% of cancer deaths occurring under the age of 65 years, many families are in the position of having to meet high outgoings, for example, mortgages and interest payments, with the probability of only one income and few unencumbered assets.

(b) Financial assistance could be administered under the Wellington Hospital Board's "Outdoor Relief Scheme". This would require a policy change from an "asset" to an "income tested" scheme.

(c) Consideration be given to increasing the "disability" allowance. Currently, the maximum amount available is $8.00.

(d) Additional funds be made available for home help assistance for those patients being nursed in their own homes.

(e) Means be found to expedite the processing of applications for social welfare benefits. It must be stressed that assistance for a terminally ill patient is usually required urgently, so some form of "fast-track" processing should be established.

(f) Consideration be given to a new category of patient, i.e. terminally ill, for the payment of the General Medical Services Benefit at an appropriate higher level to be negotiated between the Government and the New Zealand Medical Association.
(c) Hospital consultants be instructed that letters written from hospital about a terminally ill patient should be sent before the patient is discharged and should include extra information on the patient's prognosis, understanding of his illness and his reaction to it, and what further action is intended for the patient's care, see 9.6 (d).

(d) Ward charge nurses be responsible for ensuring that terminally ill patients are referred to the Community Health Nursing Service when they are discharged, and that the general practitioner is notified by telephone that the patient is returning home, see 9.6 (e).

(e) The Wellington Hospital Board encourage cooperation amongst the various services, public, private and voluntary, see 9.7.

(f) An approach be made to the Department of Health for commissioning funds for:

(i) A terminal care specialist attached to the Wellington and Kenepuru hospitals, preferably having an academic appointment, see 9.7 (a) and (c).

(ii) A terminal care specialist attached to Hutt Hospital, see 9.7 (b) and (c).

(g) The Wellington Hospital Board seek ways to improve financial assistance for the terminally ill patient and family by initiating discussions with the Department of Social Welfare and the Department of Health, see Section 9.10 (b) and (d).

The Community Health Nursing Service

(h) Communications between ward staff and community health nurses be improved, so that all terminally ill patients are notified to the Community Health Nursing Service before discharge, see 9.1 (d).

(i) Community health nurses are informed of the range of services available for the terminally ill and know how to co-ordinate these services, see 9.3 (a).

(j) The Wellington Hospital Board request a study to be carried out on the manpower and conditions of service required to provide a 24-hour continuous nursing service for the terminally ill at home, see 9.3 (c).
Due consideration be given to the management and prevention of work stress in nurses caring for the terminally ill and their families, see 9.3 (b).

10.3

THE ROYAL NEW ZEALAND COLLEGE

OF GENERAL PRACTITIONERS

(a) THAT: Doctors have the responsibility to inform a terminally ill patient, and with the patient's agreement, his or her family of the diagnosis and prognosis if and when they so request, see 9.4 (a).

(b) Doctors be aware of the therapeutic possibilities in treating the terminally ill and the range of services available, see 9.4 (b).

(c) General practitioner's appreciate the central role of the community health nurse in the care of the terminally ill at home, see 9.4 (c).

(d) General practitioner's be reminded that a higher rate of benefit is available from the Department of Health for repeated visits to a patient requiring continuing care, see 9.4 (e).

(e) General practitioner's should be aware that drugs not available on the Department of Health's free list need not be paid for by the patient, see 9.4 (f).

(f) The Royal New Zealand College of General Practitioners should develop an elective period in terminal care for postgraduate training and continuing education, see 9.5 (c).

(g) General practitioner's continually assess the needs of terminally ill patients at home so that further supportive services are provided as necessary, see 9.2 (c).

(h) A general practitioner not wishing to care for a terminally ill patient is obliged to arrange care by other appropriate services, see 9.4 (b).

10.4

THE DEPARTMENT OF HEALTH

(a) THAT: The Department of Health should recognise the care of the dying and their families as a legitimate area of health care, see 9.8 (a).
(b) The Department of Health should devise specific guidelines, both nationally and regionally, for the level of services necessary for the care of the terminally ill, see 9.8 (b).

(c) The Department of Health, in conjunction with the Wellington Hospital Board and the Community Health Nursing Service, undertake a study on the manpower and conditions of service required to provide a 24-hour continuous nursing service for the terminally ill at home, see 9.3 (c).

(d) The General Medical Services Benefit should be payable on a visit to a terminally ill patient which is initiated by the doctor, see 9.4 (d).

(e) Hospice care and concepts be recognised as a part of the health service, and that there is a need for medical specialists in terminal care to be funded through the Health Service, such funding to be provided by commissioning grants. Medical specialists should form "terminal care teams" to provide a consultative service on hospital in-patients and patients at home, at the request of the general practitioner, and to work with existing hospices. They should also undertake research, see 9.7 (a) (b) (c) and (d).

(f) Where hospice beds form part of the public hospital system, their special nature and requirements should be recognised, and, where possible, community help and funds should be encouraged to maintain their special character, see 9.7 (e).

(g) The Department of Health consider a funding policy to meet the needs of the terminally ill patient, including:

(i) The extension of the Geriatric Hospital Special Assistance Scheme to all terminally ill patients, irrespective of age, see 9.9. (a).

(ii) Introduction of a new category of bed benefit to be called "Benefit for the Terminally Ill", see 9.9 (b), (c) and (d).
(iii) Investigation of other forms of financial assistance to the patient and family where financial hardship is encountered, see 9.10 (a) (b) (c) and (d).

10.5

THE DEPARTMENT OF SOCIAL WELFARE

THAT: The Department of Social Welfare investigate means of improving financial assistance to the patient and family, including a means of speeding up the processing of applications for Social Welfare benefits, see 9.10 (a), (c), (d) and (e).

10.6

THE WELLINGTON CLINICAL SCHOOL OF MEDICINE

(a) THAT: Undergraduate training in the Wellington Clinical School of Medicine should include a terminal care component and instruction in counselling, see 9.5 (a).

(b) There is a need for a terminal care specialist attached to the Wellington hospital and the Wellington Clinical School of Medicine, see 9.7 (a).

10.7

THE WELLINGTON POSTGRADUATE MEDICAL SOCIETY

THAT: Education programmes should allow for instruction in terminal care, including counselling and bereavement, see 9.5 (c).

10.8

THE ROYAL AUSTRALASIAN COLLEGE OF SURGEONS

THAT: Care of the terminally ill be included in the advanced training for Fellowship of the Royal Australasian College of Surgeons, see 9.5 (c).

10.9

MARY POTTER AND TE OMANGA HOSPICES

(a) THAT: Voluntary co-operation and co-ordination amongst all services for the terminally ill in the Wellington region be continued and extended as necessary, see 9.7.

(b) Both hospices consider the joint appointment of medical specialists in terminal illness with the appropriate public hospitals in their region, thereby linking the private, public and voluntary sectors, see 9.7 (a) and (b) and (c).
10.10 THE NEW ZEALAND MEDICAL ASSOCIATION

THAT: The New Zealand Medical Association negotiate with the Government to consider a new category of patient, i.e. terminally ill, for the payment of the General Medical Services Benefit at an appropriate higher level.

10.11 THE NEW ZEALAND NURSING COUNCIL

THAT: In basic nursing education there is a need for greater emphasis on terminal care, counselling, and bereavement, see 9.5 (b).

10.12 THE NEW ZEALAND NURSES' ASSOCIATION

(a) THA: In basic nursing education there is a need for greater emphasis on terminal care, counselling, and bereavement, see 9.5 (b).

(b) An elective period in the care of the terminally ill should be included in the appropriate post-basic nursing education programmes, see 9.5 (d).

10.13 NURSING EDUCATION AND REVIEW ADVISORY COMMITTEE

THAT: An elective period in the care of the terminally ill should be included in the appropriate post-basic nursing education programmes, see 9.5 (d).
11.0 CONCLUSION

Terminal care is the provision of a very special kind of support required by these patients and their families, and it is based above all on high quality nursing and medical services. Its aim is to maintain the patient's quality of life at the highest possible level. This involves the use of different medical techniques for the relief of symptoms; counselling for both patients and relatives; help with spiritual and social problems; and the use of para-medical disciplines such as physiotherapy, occupational therapy, and others to enhance the remaining period of life. It involves the whole range of professionals working in the health field, supported by volunteers and community and charitable organisations. Good terminal care has many facets, and high standards are more easily achieved if it is planned.

The introduction of hospice concepts into the Wellington region has mainly been due to four organisations: the Community Health Nursing Service, the two hospices, and the Wellington Division of the Cancer Society of New Zealand, which has provided encouragement and financial support for the first three. Along with this has been an increased public interest in the quality of care that terminally ill patients receive.

The need for these developments stemmed from an awareness that the traditional apparatus of care is in many circumstances inadequate for the needs of the patient dying of terminal illness. The development of a higher standard of care in the Wellington region has been mainly the result of the co-operative effort of the four bodies mentioned above. The hospice movement is now widening to include the general practitioner, who has become much more aware of the services available and the therapeutic possibilities in treating the terminally ill. There remains a need to educate hospital personnel in these techniques.

The organisation that has developed needs formal recognition and support. This inevitably involves financial help, at a time when funds for health services are limited. Nevertheless, the economies of this type of specialised service are real. Hospice bed costs are approximately 50% of those of a public hospital bed, and some of these costs can be met by community and charitable financial support.
Financial support should aim at relieving financial hardship for the terminally ill and family; ensuring the viability of the two hospices as special units for the care of the terminally ill; providing adequate staff for nursing services for care of patients at home; and providing suitably trained medical staff for the care of terminally ill patients, "wherever they may be". Such financial aims may be long term, but they would emphasize that "caring" is as much a part of the philosophy of the Health Service as prevention of disease or "curative" treatment.

It is considered by the Wellington Health Services Advisory Committee Working Group on the Care of the Terminally Ill that the recommendations put forward may not occur naturally. To ensure the continual development of care of the terminally ill, it is proposed that an "Advisory Group" be set up so that these principles are implemented in the Wellington region.

12.0 ACKNOWLEDGMENTS

Our thanks are due to Ms J.L. Harness for her dedication in setting and typing this report.
REFERENCES


6. Gray AJ. (Department of Radiotherapy & Oncology, Wellington Hospital). "The Need for a Regional Policy for the Care of the Terminally Ill". Report to the Wellington Hospital Board, June 1980.


APPENDIX I

MEMBERS OF THE PRELIMINARY WORKING GROUP

Mr C.L. Tucker (Chairman)

Mr D.T. Beetham

Dr J.D. Bonifant

Mr I. Borrin

Sister Cecilia

Mr C.T. Collins

Mrs M.D. Cooper

Dr P. Davidson

Miss V.R. Ellen

Mr H.R. Evans

Miss G.A. Grattan

Dr A.J. Gray

Dr G.B. Kiddle

Mr G.R. Laurenson

Miss P. MacInnes

Dr B.J. MacKay

Professor K.W. Newell

Mr J. Rennie

Dr M.A.W. Shepherd

Dr P.R.G. Turnbull

Miss E.J. Whiteman
Introduction

This project was instigated at the request of the Working Party on the Terminally Ill set up by the Wellington Health Services Advisory Committee (WELSAC) (see Appendix A). The Working Party was concerned with planning facilities and services for the care of the terminally ill. As an initial step towards this end they established a definition of terminal illness:

"Any progressive illness from which the patient is expected to die and in which there is no further prospect of curative treatment. A terminally ill person is one who suffers from a Terminal Illness and whose life expectancy would normally be of less than twelve months during which time access to special services may be required."

It can be seen from this definition that in order to be classified as terminally ill a person must fulfill three criteria:

1. They must be suffering from a progressive illness.
2. There must be little possibility of curative treatment.
3. They must be expected to die within the next twelve months.

Before proceeding further, the Working Party required some data about the terminally ill. We were given four objectives to research:

i) How many people were terminally ill in a year.

ii) What are some of their qualities? (eg. age, sex, diagnostic category, location.)

iii) Which services did they use?

iv) Who provided support and advice?

In our project we made no attempt to determine how many were currently terminally ill. Rather we took a group of those who had died in 1980 and tried to determine how many had died following a terminal illness. Thus we examined half of the Wellington Health District 1980 death certificates and excluded all those we thought could not possibly have suffered a terminal illness. The remaining group whom we termed "Provisionally Terminally Ill" were sampled in order to determine through general practitioners and hospital records, how many had actually suffered a terminal illness. This allowed us to develop correction factors which were applied to the Provisionally Terminally Ill group to provide an estimate of terminal illness in Wellington. This group we termed the "Estimated Terminally Ill", and information concerning the numbers, sex, diseases, and location of this group was derived.

The second part of our study consisted of 24 interviews of the relatives of those who had died following a terminal illness, in an attempt to provide some answer to the third and fourth objectives. The findings are presented to give some insight into the provision and use of services by the terminally ill. However, the smallness of the sample prevents any of the findings being extrapolated to the terminally ill in general.

The accompanying Figure 1. is a flowchart outlining the project, and giving the actual numbers involved at each step in the study.

Research Design

No attempt has been made to study the population who is currently terminally ill. The logistic demands entailed seemed excessive, and we did not consider that such a study was either necessary or desirable.

We used, instead, retrospective data obtained from a single source of statistical information, and from general practitioners and other people intimately involved with the terminal illnesses studied. We decided that the length of the interval between data collection and death from terminal illness should be the minimum consistent with a proper research design, to ensure that our retrospective statistics were as accurate as possible.
FIGURE 1  THE PROJECT

PROBLEM DEFINED

EXAMINE 1st & 3rd QUARTER OF DEATH REGISTER, TOTAL 1468

TERMINALLY ILL

TERMINALLY ILL

NO

DEFINITIVELY EXCLUDED 883

DEFINITIVELY EXCLUDED 883

YES

PROVISIONALLY INCLUDED 585

PROVISIONALLY INCLUDED 585

RANDOM SAMPLE

RANDOM SAMPLE

1st SAMPLE 71

2nd SAMPLE 35

FUNCTIONAL CARDIAC INSUFFICIENCY

FUNCTIONAL CARDIAC INSUFFICIENCY

OTHERS

OTHERS

IDENTIFY GP

IDENTIFY GP

CONTACT GP

CONTACT GP

UNTRACED 8

UNTRACED 10

EXCLUSIONS by GP 20

EXCLUSIONS by GP 15

ASK GP: TERMINALLY ILL

ASK GP: TERMINALLY ILL

YES

YES

INCLUSIONS BY GP 43

INCLUSIONS BY GP 10

REFUSED OR DELAYED 6

CORRECTION FACTOR TO BE APPLIED TO PROVISIONAL INCLUSIONS

CORRECTION DATA ON TERMINAL ILLNESS

GP's PERMISSION

SEND LETTER TO PROSPECTIVE INTERVIEWEE 37

CONTACT INTERVIEWEE 37

INTERVIEW 24

INTERVIEW DATA
(A) **Source of Information**

Medical Certificates of Causes of Death were chosen as our primary source of information. The alternative resource, which was sufficiently inclusive and uniform for consideration, was consolidated data from the National Health Statistics Centre. However, because the most recent statistics available to us were from 1979, and despite the wealth of accurate and accessible information therein, we decided to work with the more recent data of the 1980 Death Register.

We take the Wellington region to be the Wellington Health District, that area of the North Island south of the Waikanae River, and of the Himutakas.

Therefore we have examined each Death Certificate received by the Wellington, Porirua, Paraparaumu, Lower Hutt and Upper Hutt Registrars of Births, Deaths, and Marriages, during the first and third quarter (1st January to 31st March, 1st July to 30th September) of 1980.

We note that the date and place of registration does not accurately reflect the date and place of death. Thus, a few deaths which occurred during 1980 in the Wellington region were registered elsewhere. A few of the deaths registered in the first quarter actually occurred in the latter weeks of 1979, and some deaths in the latter part of the first quarter were not registered until the second quarter. The same points are made for the third quarter. No attempt has been made to correct for these factors.

The number of deaths registered in the Wellington Health District during 1980 totalled 2,655.

1,468 Certificates were examined by us.

(B) **A Working Definition of Terminal Illness**

A protocol was devised which allowed us to definitively exclude, or provisionally include, the decedents from the population who were defined as terminally ill at the date of their death.

**Exclusions**

We used the definition given, vide supra, except that all deaths within the first year of life were excluded.

The following cases were also excluded:

1. Those occurring outside the Wellington Health District.
2. Those referred to a Coroner.
3. Those with no reference to a progressive, incurable disease which might cause death.
4. Those with a presumptive terminal illness present for less than fifteen days.
5. Those with atherosclerotic disease of the cardiovascular system and/or previous myocardial infarction, but without reference to either another progressive incurable disease which might cause death, or to functional cardiac insufficiency.*
6. Those with cerebrovascular disease and/or accidents, but without other reference to a progressive incurable disease which might cause death. We realise that some of these people may have been terminally ill under the definition, but because of time constraints were unable to investigate these further.
7. Those with hypertension, asthma, alcoholism, anaemia, obesity, chronic pancreatitis, 'old age', 'general debility', 'senility', 'dementia', 'brain failure', or 'chronic brain syndrome', but without other reference to a progressive, incurable, disease which might cause death.

* The choice of "functional cardiac insufficiency", to describe cases of congestive heart failure, ventricular failure and cardiomyopathies, is somewhat arbitrary, but we shall continue to use it in this context.
Reassessment of all inclusions by one of the four examiners, after seeking professional medical advice, resulted in the further exclusion of 76 cases. These included references to polyarteritis nodosa, Parkinson's, fibrosing alveolitis, status epilepticus, diabetes insipidus, rheumatoid arthritis, and diabetes mellitus.

We note that the four examiners inevitably differed in their interpretation of exclusion criteria. We acknowledge that discrepancies are present, but believe that they are minimal.

Total exclusions numbered 883 cases, which is 60% of the certificates examined. Table 1 provides a breakdown of these exclusions into the above categories.

### Table 1: Exclusion from TI Definition

<table>
<thead>
<tr>
<th></th>
<th>1st &amp; 3rd Quarter, 1980</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wellington</td>
<td></td>
</tr>
<tr>
<td>Sudden Cardiac Deaths</td>
<td>140</td>
</tr>
<tr>
<td>Acute Infections</td>
<td>72</td>
</tr>
<tr>
<td>C V A</td>
<td>47</td>
</tr>
<tr>
<td>Others</td>
<td>28</td>
</tr>
<tr>
<td>Coroners</td>
<td>154</td>
</tr>
<tr>
<td>Less than 12 months of Age</td>
<td>9</td>
</tr>
<tr>
<td>Other Places</td>
<td>5</td>
</tr>
<tr>
<td>TOTAL EXCLUSIONS</td>
<td>455</td>
</tr>
<tr>
<td>Lower Hutt</td>
<td></td>
</tr>
<tr>
<td>Sudden Cardiac Deaths</td>
<td>87</td>
</tr>
<tr>
<td>Acute Infections</td>
<td>44</td>
</tr>
<tr>
<td>C V A</td>
<td>23</td>
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<tr>
<td>Others</td>
<td>27</td>
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<tr>
<td>Coroners</td>
<td>39</td>
</tr>
<tr>
<td>Less than 12 months of Age</td>
<td>2</td>
</tr>
<tr>
<td>Other Places</td>
<td>5</td>
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<tr>
<td>TOTAL EXCLUSIONS</td>
<td>227</td>
</tr>
<tr>
<td>Paraparaudui</td>
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</tr>
<tr>
<td>Sudden Cardiac Deaths</td>
<td>17</td>
</tr>
<tr>
<td>Acute Infections</td>
<td>6</td>
</tr>
<tr>
<td>C V A</td>
<td>6</td>
</tr>
<tr>
<td>Others</td>
<td>3</td>
</tr>
<tr>
<td>Coroners</td>
<td>7</td>
</tr>
<tr>
<td>Less than 12 months of Age</td>
<td>1</td>
</tr>
<tr>
<td>Other Places</td>
<td>3</td>
</tr>
<tr>
<td>TOTAL EXCLUSIONS</td>
<td>43</td>
</tr>
<tr>
<td>Porirua</td>
<td></td>
</tr>
<tr>
<td>Sudden Cardiac Deaths</td>
<td>27</td>
</tr>
<tr>
<td>Acute Infections</td>
<td>19</td>
</tr>
<tr>
<td>C V A</td>
<td>12</td>
</tr>
<tr>
<td>Others</td>
<td>8</td>
</tr>
<tr>
<td>Coroners</td>
<td>41</td>
</tr>
<tr>
<td>Less than 12 months of Age</td>
<td>2</td>
</tr>
<tr>
<td>Other Places</td>
<td>3</td>
</tr>
<tr>
<td>TOTAL EXCLUSIONS</td>
<td>112</td>
</tr>
<tr>
<td>Upper Hutt</td>
<td></td>
</tr>
<tr>
<td>Sudden Cardiac Deaths</td>
<td>11</td>
</tr>
<tr>
<td>Acute Infections</td>
<td>14</td>
</tr>
<tr>
<td>C V A</td>
<td>3</td>
</tr>
<tr>
<td>Others</td>
<td>2</td>
</tr>
<tr>
<td>Coroners</td>
<td>11</td>
</tr>
<tr>
<td>Less than 12 months of Age</td>
<td>3</td>
</tr>
<tr>
<td>Other Places</td>
<td>2</td>
</tr>
<tr>
<td>TOTAL EXCLUSIONS</td>
<td>46</td>
</tr>
<tr>
<td>TOTAL</td>
<td>282</td>
</tr>
<tr>
<td>Sudden Cardiac Deaths</td>
<td>155</td>
</tr>
<tr>
<td>Acute Infections</td>
<td>91</td>
</tr>
<tr>
<td>C V A</td>
<td>68</td>
</tr>
<tr>
<td>Others</td>
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</tr>
<tr>
<td>Less than 12 months of Age</td>
<td>18</td>
</tr>
<tr>
<td>Other Places</td>
<td>8</td>
</tr>
<tr>
<td>TOTAL EXCLUSIONS</td>
<td>883</td>
</tr>
</tbody>
</table>

**Provisional Inclusions**

The "provisional inclusions" can be classified on the basis of one of four disease groupings. These are 'cancer', 'functional cardiac insufficiency', 'chronic obstructive respiratory diseases', and 'others'.

Many cases qualified for classification into more than one disease grouping. We followed the policy of classifying all cases with cancer into the 'cancer' grouping; all cases with functional cardiac insufficiency but without cancer into the 'functional cardiac insufficiency' grouping; cases of respiratory disease but without cancer or functional cardiac insufficiency into the 'chronic obstructive respiratory disease' grouping, and all other cases into the 'others' grouping.

There are 585 such inclusions (40% of certificates examined) which are presented in Table 2. Analysis of this population was undertaken.

Table 3 relates duration of illness with the disease groupings. Note that most terminal illnesses lasted longer than 12 months. 51% of cancer patients, 64% of cardiac patients, 98% of chronic obstructive airways disease patients, and 66% of the 'others' had illnesses of longer than twelve months' duration.

Table 4 shows where the terminally ill lived.

Table 5 relates the age at death with the disease groupings. There are three points of interest:

(i) 41% of the cancer patients, 13% of the cardiac patients, 10% of the chronic obstructive respiratory disease patients, and 36% of the "others" were under 65 years of age at the time of death.

(ii) The mean age at the time of death for the cancer patients is ten years less than for the cardiac and chronic obstructive respiratory disease patients.

(iii) There were few terminal illnesses below 29 years of age.
TABLE 2

INCLUSIONS IN TERMINAL ILLNESS DEFINITIONS FROM DEATH REGISTRATIONS
DEATH REGISTRATION OFFICE AND DIAGNOSIS
FIRST AND THIRD QUARTER

<table>
<thead>
<tr>
<th></th>
<th>CANCER</th>
<th>CARDIAC DISEASE</th>
<th>CORD</th>
<th>OTHERS</th>
<th>TOTAL M/F</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wellington</td>
<td>71</td>
<td>34</td>
<td>40</td>
<td>14</td>
<td>15</td>
<td>152</td>
</tr>
<tr>
<td></td>
<td>72</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>141</td>
</tr>
<tr>
<td>Lower Hutt</td>
<td>49</td>
<td>34</td>
<td>16</td>
<td>13</td>
<td>4</td>
<td>82</td>
</tr>
<tr>
<td></td>
<td>40</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>67</td>
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<td>Porirua</td>
<td>22</td>
<td>17</td>
<td>8</td>
<td>10</td>
<td>2</td>
<td>42</td>
</tr>
<tr>
<td></td>
<td>17</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>25</td>
</tr>
<tr>
<td>Paraparaumu</td>
<td>11</td>
<td>7</td>
<td>4</td>
<td>5</td>
<td>1</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td>7</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>16</td>
</tr>
<tr>
<td>Upper Hutt</td>
<td>10</td>
<td>7</td>
<td>7</td>
<td>4</td>
<td>1</td>
<td>22</td>
</tr>
<tr>
<td></td>
<td>7</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>18</td>
</tr>
<tr>
<td>Total Males/Females</td>
<td>163</td>
<td>137</td>
<td>65</td>
<td>71</td>
<td>19</td>
<td>318</td>
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<td></td>
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<td>267</td>
</tr>
<tr>
<td>Total</td>
<td>300</td>
<td>143</td>
<td>98</td>
<td>44</td>
<td></td>
<td>585</td>
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</table>

TABLE 3

INCLUSIONS IN TERMINAL ILLNESS DEFINITIONS FROM DEATH REGISTRATIONS
DURATION OF ILLNESS AND DIAGNOSIS
FIRST AND THIRD QUARTER 1980

<table>
<thead>
<tr>
<th></th>
<th>CANCER</th>
<th>CARDIAC</th>
<th>CORD</th>
<th>OTHER</th>
<th>TOTALS</th>
<th>TOTAL</th>
</tr>
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<tbody>
<tr>
<td>2-4 Weeks</td>
<td>2</td>
<td>2</td>
<td>5</td>
<td>-</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>1-3 Months</td>
<td>7</td>
<td>5</td>
<td>7</td>
<td>1</td>
<td>2</td>
<td>15</td>
</tr>
<tr>
<td>3-6 Months</td>
<td>19</td>
<td>16</td>
<td>4</td>
<td>-</td>
<td>1</td>
<td>25</td>
</tr>
<tr>
<td>6-12 Months</td>
<td>27</td>
<td>26</td>
<td>3</td>
<td>2</td>
<td>2</td>
<td>32</td>
</tr>
<tr>
<td>1 Year Plus</td>
<td>85</td>
<td>69</td>
<td>43</td>
<td>48</td>
<td>25</td>
<td>11</td>
</tr>
<tr>
<td>Uncertain</td>
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<td>19</td>
<td>7</td>
<td>12</td>
<td>2</td>
<td>35</td>
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<tr>
<td>Total</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>585</td>
</tr>
</tbody>
</table>
### TABLE 4

**Provisional Terminal Illness**  
First and Third Quarters 1980  
Location and Diagnostic Category

<table>
<thead>
<tr>
<th>HOME ADDRESS</th>
<th>CANCER</th>
<th>CARDIAC DISEASE</th>
<th>CORD</th>
<th>OTHERS</th>
<th>TOTAL</th>
<th>PROPORTION OF TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wellington</td>
<td>49</td>
<td>52</td>
<td>25</td>
<td>30</td>
<td>108</td>
<td>36%</td>
</tr>
<tr>
<td>Lower Hutt,</td>
<td>58</td>
<td>41</td>
<td>19</td>
<td>27</td>
<td>98</td>
<td>31%</td>
</tr>
<tr>
<td>Inc. Stokes</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Valley</td>
<td></td>
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<td></td>
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<tr>
<td>Eastbourne,</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mainiowata</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Upper Hutt,</td>
<td>10</td>
<td>14</td>
<td>5</td>
<td>8</td>
<td>27</td>
<td>10%</td>
</tr>
<tr>
<td>Inc. Silverstream</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Porirua</td>
<td>21</td>
<td>12</td>
<td>9</td>
<td>8</td>
<td>44</td>
<td>11%</td>
</tr>
<tr>
<td>Inc. Tawa,</td>
<td></td>
<td></td>
<td></td>
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<td>Johnsonville</td>
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<td>Newlands</td>
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<td>West Coast</td>
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</tr>
<tr>
<td>Plimmerton</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>To Maikanae</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Elsewhere</td>
<td>4</td>
<td>5</td>
<td>2</td>
<td>-</td>
<td>6</td>
<td>2%</td>
</tr>
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</table>

TOTAL = 585

### TABLE 5

**Provisionally Terminally Ill: Diagnosis/Age at Death**

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<tr>
<th></th>
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<tbody>
<tr>
<td>Cancer</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>6</td>
<td>5</td>
<td>8</td>
<td>8</td>
<td>20</td>
<td>38</td>
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<td>18</td>
<td>12</td>
<td>10</td>
<td>300</td>
<td>66</td>
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<td>Cardiac</td>
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<td></td>
<td>3</td>
<td>6</td>
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<td>19</td>
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<td>143</td>
<td>77</td>
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<tr>
<td>CORD</td>
<td>2</td>
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<td>10</td>
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<td></td>
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<td></td>
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<tr>
<td>Others</td>
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<td>2</td>
<td>1</td>
<td>5</td>
<td>4</td>
<td>6</td>
<td>6</td>
<td>7</td>
<td>2</td>
<td>4</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td>44</td>
<td>67</td>
<td></td>
</tr>
</tbody>
</table>
VALIDATION OF THE PROVISIONALLY TERMINALLY ILL GROUP

It is obvious that we had provisionally included cases in each grouping which would be excluded were more information to become available. However, we did not feel justified in making any further exclusions on the information recorded on the Medical Certificate of Causes of Death.

We decided to select a first random sample of 71 of our provisional inclusions stratified by the groups Cancer, Functional Cardiac Insufficiency, Chronic Obstructive Respiratory Disease, and "Others", with the aim of

(i) validating the terminally ill group
(ii) interviewing the relatives of the decedent.

Working with this sample we identified the decedent’s GP from hospital records and the Death Certificates themselves.

We contacted the General Practitioners by telephone to confirm or disconfirm that their patients were "terminally ill" by the definition given in the problem statement.

We were able to trace the GPs involved in 63 cases (88%), and it became evident that large proportions of the non-cancer "provisionally terminally ill" were being excluded. Because the sample had been representatively stratified for the interviews (See Table 8) there were only small numbers in each non-cancer category (17 in Cardiac, 12 in Chronic Obstructive Respiratory Disease, and 6 in "Others"). So that an accurate estimate of the proportion of truly terminally ill cases could be made the numbers in each group were boosted by randomly sampling an extra 12 in cardiac, 11 in CORD and 12 in "Others". A total of 25 of these extra 35 were traced, 10 being confirmed as terminally ill. These were combined with the original sample, as in Table 6.

<table>
<thead>
<tr>
<th>TABLE 6</th>
<th>SAMPLE I</th>
<th>SAMPLE II</th>
</tr>
</thead>
<tbody>
<tr>
<td>CATEGORY</td>
<td>Included</td>
<td>Excluded</td>
</tr>
<tr>
<td>CANCER</td>
<td>28</td>
<td>3*</td>
</tr>
<tr>
<td>CHF</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>CORD</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>OTHERS</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>TOTAL</td>
<td>43</td>
<td>20</td>
</tr>
</tbody>
</table>

* Breakdown of cancer exclusions: 2 prostate cancers from which GP did not expect death, and 1 cancer diagnosed only 1 week before death.

ESTIMATION OF ACTUAL TERMINAL ILLNESS

Using the figures in Table 6, the proportion of each disease category which was actually terminally ill was calculated by dividing the Number of Inclusions in each category by the Total Number of Contacts (Inclusions and Exclusions):

\[
\text{Proportion} = \frac{\text{No. of Inclusions}}{\text{No. Inclusions} + \text{No. Exclusions}} \quad \text{(See Table 7)}
\]

Note that a total of 18 cases were untraced, and this may have introduced some error to the final figures which has not been allowed for elsewhere.
TABLE 7  PROPORTION OF PROVISIONALLY INCLUDED T.I. CASES WHICH WERE FOUND TO BE TERMINALLY ILL

<table>
<thead>
<tr>
<th>CATEGORY</th>
<th>UNTRACED</th>
<th>INCLUDED</th>
<th>EXCLUDED</th>
<th>INC + EXCL TOTAL</th>
<th>INCLUDED TOTAL</th>
<th>95% CONFIDENCE INTERVAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>CANCER</td>
<td>4</td>
<td>29</td>
<td>3</td>
<td>32</td>
<td>0.91</td>
<td>(.79 , 1.0)</td>
</tr>
<tr>
<td>CARDIAC</td>
<td>4</td>
<td>9</td>
<td>16</td>
<td>24</td>
<td>0.36</td>
<td>(.17 , .55)</td>
</tr>
<tr>
<td>CORD</td>
<td>4</td>
<td>8</td>
<td>11</td>
<td>19</td>
<td>0.42</td>
<td>(.19 , .65)</td>
</tr>
<tr>
<td>OTHERS</td>
<td>4</td>
<td>9</td>
<td>5</td>
<td>14</td>
<td>0.64</td>
<td>(.40 , .89)</td>
</tr>
</tbody>
</table>

This proportion was used to calculate an estimation of the number of each category of our "provisionally terminally ill" cases which should be considered actually terminally ill (See Table 8).

TABLE 8  CORRECTED TERMINALLY ILL INCLUSIONS

<table>
<thead>
<tr>
<th>% of Total Inclusions</th>
<th>Sampling Ratio for Interview</th>
<th>Final Sampling Ratio</th>
<th>No. of Inclusions</th>
<th>Correction Factors I/TIE</th>
<th>Corrected Inclusions</th>
<th>Upper &amp; Lower Limits, (95% Confidence Interval)</th>
</tr>
</thead>
<tbody>
<tr>
<td>CANCER</td>
<td>51%</td>
<td>1:8.3</td>
<td>1:8.3</td>
<td>300</td>
<td>0.91</td>
<td>272</td>
</tr>
<tr>
<td>CARDIAC</td>
<td>24%</td>
<td>1:8.4</td>
<td>1:6.0</td>
<td>143</td>
<td>0.36</td>
<td>51</td>
</tr>
<tr>
<td>CORD</td>
<td>17%</td>
<td>1:8.2</td>
<td>1:4.5</td>
<td>98</td>
<td>0.42</td>
<td>41</td>
</tr>
<tr>
<td>OTHERS</td>
<td>8%</td>
<td>1:7.3</td>
<td>1:3.7</td>
<td>44</td>
<td>0.64</td>
<td>28</td>
</tr>
<tr>
<td>TOTAL</td>
<td></td>
<td></td>
<td></td>
<td>585</td>
<td></td>
<td>392</td>
</tr>
</tbody>
</table>

To determine the number of deaths from terminal illness in Wellington per annum, the first and third quarter Terminal Illness totals were divided by their proportion of the total deaths for 1980.

Total 1st & 3rd quarter TI deaths = 392
(confidence interval 298 - 482)

Proportion of annual deaths considered = 1468/2655
(i.e. deaths in 1st & 3rd quarter over total death registrations)

Total TI Wellington Region = 2655 x 392 = 709 during 1980

Limits
Upper - 872
Lower - 539
To estimate the prevalence of terminal illness in the Wellington Region a figure was obtained for the average duration of the terminal illness, using the "interval between diagnosis and death" information recorded on the death certificate, making an upper limit of twelve months in accordance with the definition. This figure of 44 weeks was very close to the figure obtained from our interview data, of 47 weeks.

This gave a prevalence of $P = \frac{44}{52} \times 709 = 600$

with confidence limits of 456 and 738.

The correction factors were applied to Table 4, to obtain a corrected total for the 1st and 3rd quarters. From this, the incidence and prevalence of terminal illness in each location per annum has been estimated. (See Tables 9 and 10). Table 9 shows a breakdown of the place of death by diagnostic category. The main point of this last table is that in our estimated terminally ill group there were cancer deaths only, occurring in the hospices.

Further calculations using correction factors indicated that 46% of the terminally ill were female, and 34% were under 65.

These final estimates and their confidence intervals have been worked out without knowing what bias may have been introduced by the failures to contact GPs in several cases. No clues are available as to the direction of this bias.

### Table 9

<table>
<thead>
<tr>
<th>LOCATION</th>
<th>CANCER</th>
<th>CARDIAC</th>
<th>RESP.</th>
<th>OTHERS</th>
<th>CORRECTED TOTAL</th>
<th>ESTIMATED YEARLY TOTAL</th>
<th>PREVALENCE ESTIMATE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wellington</td>
<td>91</td>
<td>20</td>
<td>14</td>
<td>12</td>
<td>137</td>
<td>248</td>
<td>210</td>
</tr>
<tr>
<td>Lower Hutt</td>
<td>90</td>
<td>17</td>
<td>10</td>
<td>8</td>
<td>125</td>
<td>226</td>
<td>191</td>
</tr>
<tr>
<td>Upper Hutt</td>
<td>22</td>
<td>5</td>
<td>6</td>
<td>4</td>
<td>37</td>
<td>67</td>
<td>57</td>
</tr>
<tr>
<td>Porirua</td>
<td>30</td>
<td>6</td>
<td>6</td>
<td>1</td>
<td>43</td>
<td>78</td>
<td>66</td>
</tr>
<tr>
<td>West Coast</td>
<td>31</td>
<td>4</td>
<td>5</td>
<td>3</td>
<td>43</td>
<td>78</td>
<td>66</td>
</tr>
<tr>
<td>Elsewhere</td>
<td>8</td>
<td>1</td>
<td>-</td>
<td>-</td>
<td>9</td>
<td>16</td>
<td>14</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>272</td>
<td>53</td>
<td>41</td>
<td>28</td>
<td>394</td>
<td>713</td>
<td>604</td>
</tr>
</tbody>
</table>

### Table 10

<table>
<thead>
<tr>
<th>DISTRICT</th>
<th>RATE PER 100,000 TOTAL POPULATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wellington</td>
<td>175</td>
</tr>
<tr>
<td>Hutt</td>
<td>218</td>
</tr>
<tr>
<td>West Coast/Porirua</td>
<td>214</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>200</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>95% CONFIDENCE LIMITS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Upper Limit</td>
</tr>
<tr>
<td>Lower Limit</td>
</tr>
</tbody>
</table>
TABLE 11

PLACE OF DEATH X DIAGNOSTIC CATEGORY

ESTIMATED CORRECTED ANNUAL INCIDENCE 1980

<table>
<thead>
<tr>
<th></th>
<th>CANCER</th>
<th>CARDIAC</th>
<th>C.O.R.D.</th>
<th>OTHER</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>WELLINGTON PUBLIC HOSPITALS</td>
<td>223</td>
<td>49</td>
<td>46</td>
<td>28</td>
<td>346</td>
</tr>
<tr>
<td>LOWER HUTT HOSPITALS</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AT HOME</td>
<td>115</td>
<td>24</td>
<td>16</td>
<td>8</td>
<td>163</td>
</tr>
<tr>
<td>MARY POTTER HOSPICES</td>
<td>72</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>72</td>
</tr>
<tr>
<td>TE OMANGA HOSPICES</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&quot;HOMES&quot; RUSSELL KEMP</td>
<td>10</td>
<td>7</td>
<td>5</td>
<td>6</td>
<td>28</td>
</tr>
<tr>
<td>AROMA OF COMPASSION</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PRIVATE HOSPITALS</td>
<td>7</td>
<td>10</td>
<td>1</td>
<td>3</td>
<td>21</td>
</tr>
<tr>
<td>&quot;CALVARY&quot;</td>
<td>66</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>68</td>
</tr>
<tr>
<td>SILVERSTREAM PARAPARAUM HOSPITALS</td>
<td>0</td>
<td>2</td>
<td>8</td>
<td>3</td>
<td>13</td>
</tr>
<tr>
<td>TOTAL</td>
<td>493</td>
<td>92</td>
<td>75</td>
<td>50</td>
<td>711</td>
</tr>
</tbody>
</table>

NB 2 died outdoors

THE INTERVIEW

The General Practitioners traced in the initial sample (See Sample, Table 6) were asked for permission to contact the relevant next of kin or closest friend of the decedents remaining in our sample.

Permission was refused in three cases out of 71 (7% of those traced). Comments accompanying the refusals included: "taking up old coals", "leaving me to pick up the pieces", "I'm very upset about this patient's death myself", and "an interview would not be desirable for the spouse at this time".

A letter was then posted in the agreed cases, to the address obtained from hospital records or Death Certificates, and verified by the General Practitioner involved. (See Appendix A for letter)

We were not able to conduct interviews with 13 of these contacts.

6 did not answer repeated telephone calls
1 phone number was changed to a confidential number
1 had moved to Napier
5 did not wish to be interviewed; one of these did not consider that his wife had been terminally ill, and in another case, no mutually convenient time could be arranged for the interview.

It is important to realise that due to the limitations of time only 24 relatives/friends of the deceased were interviewed. This information is therefore only an indication of the feelings and experiences of a very few people involved in a terminal illness, and as such cannot be used to extrapolate into a larger population.
It was decided that the best way to conduct a sensitive interview and obtain the information required was to encourage people to tell their own story. With this in mind, five basic open-ended questions were asked (Nos. 4, 5, 6, 7 & 8). The interviewer used the remaining parts of the questionnaire as a guide to the course of the interview and the type of information required, as a framework for recording information and as a source of direct questions if the required information was not delivered spontaneously. Some interviewers filled in the questionnaire during the interview, others after they left.

SEE APPENDIX B FOR QUESTIONNAIRE

RESULTS

The response data presented here follow in the order of the questions posed in the Questionnaire.

1. What is your relationship to ?

This question was basically a conversation starter but was also designed to check up on the nature of the relationships.

<table>
<thead>
<tr>
<th>CATEGORY</th>
<th>NO.</th>
</tr>
</thead>
<tbody>
<tr>
<td>FATHER</td>
<td>1</td>
</tr>
<tr>
<td>MOTHER</td>
<td>0</td>
</tr>
<tr>
<td>HUSBAND</td>
<td>5</td>
</tr>
<tr>
<td>WIFE</td>
<td>5</td>
</tr>
<tr>
<td>SON</td>
<td>3</td>
</tr>
<tr>
<td>DAUGHTER</td>
<td>9</td>
</tr>
<tr>
<td>OTHER (GRAND-DAUGHTER)</td>
<td>1</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>24</strong></td>
</tr>
</tbody>
</table>

2. Who else is in the family?

The aim of this question was both to help establish an easy relationship with the contact and to obtain some idea of the supportive nature of the family. Where obvious implications of support or lack of it were made, they were included in the appropriate category; e.g., lives alone in Wellington and separated from wife and four children; family very supportive after the death.

<table>
<thead>
<tr>
<th>FAMILY SUPPORT</th>
<th>NO.</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADEQUATE SUPPORT</td>
<td>6</td>
</tr>
<tr>
<td>NON-ADEQUATE SUPPORT</td>
<td>6</td>
</tr>
<tr>
<td>DON'T KNOW</td>
<td>12</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>24</strong></td>
</tr>
</tbody>
</table>
3. How long was your ill, such that he/she was unable to continue to lead his/her normal life?

The aim of this question was to get an indication of the time that people may require services (including time before the terminal nature of the illness was known), and the place where this time was spent.

<table>
<thead>
<tr>
<th>Duration of Illness</th>
<th>No.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 - 2 Weeks</td>
<td>3</td>
</tr>
<tr>
<td>1 - 3 Months</td>
<td>6</td>
</tr>
<tr>
<td>4 - 9 Months</td>
<td>4</td>
</tr>
<tr>
<td>1 - 4 Years</td>
<td>6</td>
</tr>
<tr>
<td>5 - 10 Years</td>
<td>3</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>22*</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Place of Illness</th>
<th>No.</th>
</tr>
</thead>
<tbody>
<tr>
<td>At Home Alone</td>
<td>2</td>
</tr>
<tr>
<td>At Home with Next-of-Kin</td>
<td>16*</td>
</tr>
<tr>
<td>At Hospital</td>
<td>4</td>
</tr>
<tr>
<td>At Hospice</td>
<td>1</td>
</tr>
<tr>
<td>Old Folks Home</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>24</td>
</tr>
</tbody>
</table>

*2 unknown

4. Could you tell me something about how you and your found out that he/she didn't have very long to live?

The aim of this question was to learn about families' experiences when being told of the terminal nature of the illness and their feelings about that experience. The basic division was into those who were not told, and those who were told.

A. No. of People Not Told = 7

<table>
<thead>
<tr>
<th>Feeling About Not Being Told</th>
<th>No.</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Satisfied</td>
<td>4</td>
<td>- 3 felt fine because the doctors didn't expect the patient to die and therefore couldn't have told anyone.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- I said that it was tacit knowledge for all concerned and they felt fine about this</td>
</tr>
<tr>
<td>DISSATISFIED</td>
<td>2</td>
<td>- I &quot;would have preferred to have been told&quot;.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- I was bitter that not told.</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>6*</td>
<td></td>
</tr>
</tbody>
</table>

*1 had no comment

Of these seven people: - in 3 cases the patient assumed or guessed he/she was dying. - in 3 cases the next of kin " the patient" - one had no comment
B. No. of People Told = 17

Range of time between known diagnosis and death: 4 years + 2 days
Average time between known diagnosis and death: 46 weeks (approx)

<table>
<thead>
<tr>
<th>TIME</th>
<th>NO. OF PEOPLE</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 - 4 YEARS</td>
<td>5</td>
</tr>
<tr>
<td>6 - 12 MONTHS</td>
<td>2</td>
</tr>
<tr>
<td>2 MONTHS</td>
<td>2</td>
</tr>
<tr>
<td>1 - 4 WEEKS</td>
<td>6</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>15</strong></td>
</tr>
</tbody>
</table>

*2 unknown

<table>
<thead>
<tr>
<th>PLACE INFORMATION REC.</th>
<th>NO.</th>
</tr>
</thead>
<tbody>
<tr>
<td>IN HOSPITAL</td>
<td>14</td>
</tr>
<tr>
<td>AT HOME</td>
<td>1</td>
</tr>
<tr>
<td>AT HOSPICE</td>
<td>1</td>
</tr>
<tr>
<td>GP'S CLINIC</td>
<td>1</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>17</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>INF.RECEIVED FROM:</th>
<th>NO.</th>
</tr>
</thead>
<tbody>
<tr>
<td>G.P.</td>
<td>2</td>
</tr>
<tr>
<td>HOSPITAL DOCTOR</td>
<td>13</td>
</tr>
<tr>
<td>MINISTER OF RELIGION</td>
<td>0</td>
</tr>
<tr>
<td>NURSING STAFF</td>
<td>1</td>
</tr>
<tr>
<td>OTHER (HOSPICE DOCTOR)</td>
<td>1</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>17</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>INFORMATION GIVEN TO:</th>
<th>NO.</th>
<th>PASSED ON?</th>
</tr>
</thead>
</table>
| PATIENT ALONE          | 2   | 1 - Patient told next of kin  
|                        |     | 2 - Hospital doctor told next of kin |
| NEXT OF KIN ALONE      | 8   | 1 - Next of kin told patient  
| (3 requested information as impending death had been assumed by patient or both patient and next of kin) | 2 - Hospital Dr. told patient  
|                        |     | 5 - Family elected not to tell patient  
|                        |     | 4 of these thought the patient had guessed before he died; 1 was not sure if the doctors had told the patient. |
| PATIENT & NEXT OF KIN TOG. | 3   |          |
| NEXT OF KIN & FAMILY TOGETHER | 4   | 1 - Patient requested information from hospital doctor and was told  
|                                    |     | 2 - Families decided not to tell patient  
|                                    |     | 6 both families thought the patient had guessed.  
|                                    |     | 1 - Patient did not receive a direct message but next of kin said patient knew. |
| **TOTAL**                 | **17** |          |
FEELINGS ABOUT WAY TOLD:

<table>
<thead>
<tr>
<th>BASIC FEELING</th>
<th>NO.</th>
<th>COMMENT (Some people made more than 1 point)</th>
</tr>
</thead>
<tbody>
<tr>
<td>SATISFIED</td>
<td>11</td>
<td>4 - glad next of kin told alone</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2 - glad told together</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3 - happy to request information</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1 - assumed implications after told diagnosis</td>
</tr>
<tr>
<td>DISSATISFIED</td>
<td>5</td>
<td>1 - unhappy not told earlier</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2 - unhappy because euphemisms used for cancer</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2 - unhappy because had to extract information</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2 - unhappy because patient told alone</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1 - unhappy because doctor blunt and no privacy in hospital</td>
</tr>
<tr>
<td>MIXED</td>
<td>1</td>
<td>1 - unhappy not told early</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1 - unhappy patient told alone</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1 - happy that doctor kind in delivering information</td>
</tr>
<tr>
<td>TOTAL</td>
<td>17</td>
<td></td>
</tr>
</tbody>
</table>

IDEAL WAY OF BEING TOLD:

Number NOT desiring changes: 9
Number desiring changes: 12 Comments:
- 6 wanted to hear earlier what was happening
- 5 wanted information to be in clear lay language
- 4 wanted next of kin to be told alone: of these 2 then wanted Dr to tell the family and patient together
- 2 wanted Dr to tell patient and concerned family together

TOTAL 21

*3 people who were not told had no opinion.

CONCLUSIONS

The majority of people are told of the terminal nature of the illness, mostly by a hospital doctor in a hospital. The next of kin is told alone most often and the majority of these people elected not to tell the patient, while at the same time thinking that the patient had guessed.

The majority of people, whether told or not told, expressed satisfaction about the amount of information they received. However, the majority of all interviewees would have wanted to have changed something about the way they were told in order for it to be ideal.

Of those expressing dissatisfaction the major criticisms included the necessity to extract information, euphemisms used by medical people for cancer, late receipt of information, and the use of unclear medical language.
As well as talking specifically about how seriously ill your ___ was, families often feel they need to know what to expect during the illness and of the treatments. Can you tell me about any talks like that you had with anybody?

(a) Medical person made offer to discuss illness, treatment outcomes in 9 cases - 2 GPs, 7 Specialists.

Of these - 4 freely answered questions throughout patient's terminal illness
- 5 offered only late in progress of condition (eg. post-operatively) but 4 seemed fully satisfied with this.

Also, 2 contacts said doctors would only discuss patient's condition, not treatment or its side effects.

2 perceived doctors as evasive in response to questions regarding possibility of cancer.

2 praised GPs availability for discussion/support, but one was angry that specialists were not so forthcoming.

(b) No offer was made in 15 cases.

Of these - 11 patients (or next of kin) asked no further
- 4 actively questioned.

(i) of the 4 "questioners" all four expected more directness from doctors,
2 proceeded to ask elsewhere
1 said "used Dr's facial expression" to clarify information given.

(ii) of the 11 "no questioners"
5 trusted doctors enough to ask no further
3 families "knew patient was terminal, so other information no extra benefit to anyone" 3 would have asked if doctors more approachable - one mentioned not being able to see doctor separately from patient.

Combining these Sections:
8 of 9 satisfied with medical information volunteered
none of 4 were satisfied who actively questioned
8 of 11 were satisfied who did not seek out advice
16 of 24 were satisfied with information received during discussions of illness and therapy.

Regarding therapy given to patients:

<table>
<thead>
<tr>
<th>TREATMENT</th>
<th>NUMBERS</th>
</tr>
</thead>
<tbody>
<tr>
<td>SURGICAL</td>
<td>9</td>
</tr>
<tr>
<td>MEDICAL</td>
<td>7</td>
</tr>
<tr>
<td>RADIOTHERAPY</td>
<td>7</td>
</tr>
<tr>
<td>CHEMOTHERAPY</td>
<td>2</td>
</tr>
<tr>
<td>PAIN RELIEF ONLY</td>
<td>1</td>
</tr>
<tr>
<td>URINARY CATHETERISATION</td>
<td>1</td>
</tr>
</tbody>
</table>
Two had particular comments.

(1) Post-pneumonectomy one patient was receiving radiotherapy - kin never found out why this was needed - only told "she's now clear of tumour". They were concerned that it hastened her decline.

(2) Another was concerned that no forewarning was given of side effects of radiotherapy - patient was collapsing (fainting) some three times per day.

Another aspect of care is relief of the pain patients undergo, and investigating this we came up with the following:

<table>
<thead>
<tr>
<th>DURATION OF PATIENT PAIN</th>
<th>NUMBER</th>
</tr>
</thead>
<tbody>
<tr>
<td>UNKNOWN TO INTERVIEWEE</td>
<td>7</td>
</tr>
<tr>
<td>ONE WEEK</td>
<td>1</td>
</tr>
<tr>
<td>SEVERAL MONTHS</td>
<td>9</td>
</tr>
<tr>
<td>MORE THAN ONE YEAR</td>
<td>7</td>
</tr>
</tbody>
</table>

Of those suffering pain:

<table>
<thead>
<tr>
<th>APPROX. DEGREE OF PAIN</th>
<th>NUMBER</th>
</tr>
</thead>
<tbody>
<tr>
<td>NONE</td>
<td>4</td>
</tr>
<tr>
<td>VERY LITTLE</td>
<td>5</td>
</tr>
<tr>
<td>REASONABLE</td>
<td>3</td>
</tr>
<tr>
<td>QUITE SEVERE</td>
<td>7</td>
</tr>
<tr>
<td>VERY SEVERE</td>
<td>3</td>
</tr>
<tr>
<td>INTERVIEWEE UNSURE</td>
<td>2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>ADEQUACY OF PAIN RELIEF</th>
<th>NUMBER</th>
</tr>
</thead>
<tbody>
<tr>
<td>UNKNOWN TO INTERVIEWEE</td>
<td>8</td>
</tr>
<tr>
<td>TOTALLY INADEQUATE</td>
<td>1</td>
</tr>
<tr>
<td>INADEQUATE</td>
<td>1</td>
</tr>
<tr>
<td>ADEQUATE</td>
<td>8</td>
</tr>
<tr>
<td>VERY GOOD</td>
<td>2</td>
</tr>
<tr>
<td>EXCELLENT</td>
<td>2</td>
</tr>
</tbody>
</table>

*2 patients required no pain relief

<table>
<thead>
<tr>
<th>TYPE OF PAIN RELIEF</th>
<th>NUMBER</th>
</tr>
</thead>
<tbody>
<tr>
<td>OPIATE ANALGESICS - INJECTION</td>
<td>7</td>
</tr>
<tr>
<td>OPIATE ANALGESICS - ORAL</td>
<td>1</td>
</tr>
<tr>
<td>OTHER ANALGESICS (INC. SRA)</td>
<td>5</td>
</tr>
<tr>
<td>SURGICAL OPERATION</td>
<td>1</td>
</tr>
<tr>
<td>OTHER - TRINITRIN, CHLORPROMAZINE, ETC.</td>
<td>3</td>
</tr>
<tr>
<td>UNKNOWN TO NEXT OF KIN</td>
<td>1</td>
</tr>
</tbody>
</table>
Of the opiate injections, three patients were able to have the injection administered by their own family, others by district or hospital nurses, one only required pre-operative pain relief.

Relevant Comments

Evidently simpler regimes would improve the pain relief aspect of patient care. Ensuring better comprehension by the patient and family of the condition and pertinent needs would improve compliance and general satisfaction. Some individuals required stronger analgesics or increased dosages as the course of the terminal illness progressed.

Overall, relief of patients' pain was one of the most satisfactory aspects of total terminal care. Among our contact families only 2 of 16 expressed dissatisfaction, while 8 were either unsure or unaware of the pain relief given, and whether or not the relief was satisfactory.

6. When someone is very ill they and their family often find that they have special needs, for example, they may have financial difficulties, they may need help with cooking and laundry, they may need someone to talk to.

Question 6 was asking the next-of-kin about needs that arose during the time their relative was terminally ill, how these needs were fulfilled, and how they found out about groups who could fulfil these needs.

Could you tell me something about any needs that you felt you and your family had during those last months?

**Needs arising for Patient and Family**

<table>
<thead>
<tr>
<th>PRACTICAL HELP</th>
<th>FAMILY SUPPORT</th>
<th>COUNSELLING</th>
<th>FINANCIAL NEEDS</th>
<th>HOSPICE AID</th>
<th>NONE</th>
</tr>
</thead>
<tbody>
<tr>
<td>31</td>
<td>9</td>
<td>11</td>
<td>2</td>
<td>2</td>
<td>4</td>
</tr>
</tbody>
</table>

PRACTICAL HELP - Includes such categories as cooking meals, laundry, bathing the patient, etc.

FAMILY SUPPORT - This was actually the number of people who said they had family support, and as this offset other needs, it has been included in the table as a need that arose and was fulfilled.

COUNSELLING - This included support from church groups and also support from GPs.

NONE - One person in this group felt that without good family support outside aid was valueless.

- Two people said the dying relative was in hospital so they had no needs.
- One person said they were able to cope with the dying relative and still keep the other areas of their life going reasonably normally.

*Note If a service was used, without the next-of-kin mentioning this as a specific need that arose, it was included as a need arising in the family anyway.

Comments on the Needs

Ten people felt that having family support offset quite a few needs as jobs could be shared around the family. Also the family was good as a counselling service where members felt quite safe saying how they really felt.

Five of these people felt strongly that the family should fulfil all the needs and that bringing in outsiders was either an admission of defeat or that outside help would be ineffectual without family support also being there.
4 people required someone from outside to talk to about what was happening in their lives and a further 2 had their GP visiting them regularly to fulfil this role.

14 people required someone to come into the house to relieve them for a while so that they could go for a walk, go shopping, or just do cleaning around the house. 6 of the people wanted help with laundry, bathing the patient, dressing the patient, and 3 people would have liked to have had nurses either living in full time, or staying overnight so the family could get some sleep. 2 people felt so unable to cope that either the ill person or the ill person's spouse had to be admitted to a rest home.

What group(s) outside the immediate family did you first go to, to meet these needs? Did you use any further group(s) later on?

<table>
<thead>
<tr>
<th>SERVICES USED</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wellington Hospital Board</td>
</tr>
<tr>
<td>Hospital Services</td>
</tr>
<tr>
<td>Community Health Services</td>
</tr>
<tr>
<td>Department of Social Welfare</td>
</tr>
<tr>
<td>ACC</td>
</tr>
<tr>
<td>General Practitioners</td>
</tr>
<tr>
<td>Domiciliary Nursing Trust</td>
</tr>
<tr>
<td>Practice Nurses</td>
</tr>
<tr>
<td>Night Nurses (Nursing Bureau)</td>
</tr>
<tr>
<td>Cancer Society</td>
</tr>
<tr>
<td>Church Groups</td>
</tr>
<tr>
<td>Clergy</td>
</tr>
<tr>
<td>Baptist Social Services</td>
</tr>
<tr>
<td>Catholic Social Services</td>
</tr>
<tr>
<td>Methodist Social Services</td>
</tr>
<tr>
<td>Presbyterian Social Services</td>
</tr>
<tr>
<td>Salvation Army Social Services</td>
</tr>
<tr>
<td>Wellington City Mission</td>
</tr>
<tr>
<td>NZ Council for Christian Social Services</td>
</tr>
<tr>
<td>St Vincent de Paul Guild</td>
</tr>
<tr>
<td>Jewish Care of the Aged</td>
</tr>
<tr>
<td>Community Centres, Resource Centres or Health Centres</td>
</tr>
<tr>
<td>Brooklyn</td>
</tr>
<tr>
<td>Kilbirnie</td>
</tr>
<tr>
<td>Newtown</td>
</tr>
<tr>
<td>Bereaved Parents Group</td>
</tr>
<tr>
<td>Widows and Widowers Association</td>
</tr>
<tr>
<td>Citizens Advice Bureau</td>
</tr>
<tr>
<td>Mothers Helpers</td>
</tr>
<tr>
<td>Samaritans</td>
</tr>
<tr>
<td>Good Samaritans</td>
</tr>
<tr>
<td>Red Cross</td>
</tr>
<tr>
<td>St John's Ambulance</td>
</tr>
<tr>
<td>Old People's Welfare Council</td>
</tr>
<tr>
<td>Maori Women's Welfare League</td>
</tr>
<tr>
<td>British Sailors Society</td>
</tr>
<tr>
<td>Care and Craft</td>
</tr>
<tr>
<td>Under Stress</td>
</tr>
<tr>
<td>Lost Chord Club</td>
</tr>
</tbody>
</table>
Help given was:  
- Totally unsatisfactory
- Unsatisfactory
- Satisfactory
- Very Satisfactory
- Excellent

<table>
<thead>
<tr>
<th>STANDARD OF HELP OF SERVICES USED:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unsatisfactory</td>
</tr>
<tr>
<td>Numbers</td>
</tr>
</tbody>
</table>

The unsatisfactory service was from a nursing home where the wife of a terminally ill man was admitted for rest by the son and daughter-in-law. One of the satisfactory services was for nursing help during the night-time and was classified as satisfactory only because the service was not available often enough.

One of the excellent services was in relation to the Mary Potter Hospice where the husband and his sick wife were welcomed as though they were members of a big family, and there was a one month follow up after the wife's death from the hospice to check on the needs of the husband.

Time occurred - in relation to known prognosis/illness

<table>
<thead>
<tr>
<th>TIME AFTER PROGNOSIS KNOWN THAT SERVICE INITIALLY USED:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Immediately</td>
</tr>
<tr>
<td>Numbers</td>
</tr>
</tbody>
</table>

This part of the question was poorly answered by the relatives, either because of poor phrasing of the question by the interviewer, or because the relatives couldn't remember the sequence of events in relation to hearing about the terminal illness.

How learned of these groups:

<table>
<thead>
<tr>
<th>SOURCE OF KNOWLEDGE OF SERVICE</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP</td>
</tr>
<tr>
<td>Initial Groups</td>
</tr>
<tr>
<td>Later Groups</td>
</tr>
</tbody>
</table>

The following comments relate to the list of services that we handed to the next of kin to look at to check off those services about which they had knowledge, and then to check those that they used. As so few comments were made, they are all reported verbatim.

"It would be a good idea if a list like this was supplied to GPs for use by patients."

"I thought we had to pay for the hospice."

"I thought the Cancer Society was for research rather than for terminal care."

"I had heard of hospices but had a preference for home care" and "for the relative to die at home."

"People should be made aware of social welfare grants."

"I could have done with help earlier." (in relation to laundry)
Did you know of any of these groups who can provide assistance with terminal illness?

Did you use any of them?

<table>
<thead>
<tr>
<th>KNOWN</th>
<th>USED</th>
</tr>
</thead>
<tbody>
<tr>
<td>8</td>
<td>5</td>
</tr>
<tr>
<td>16</td>
<td>10</td>
</tr>
<tr>
<td>10</td>
<td>5</td>
</tr>
<tr>
<td>8</td>
<td>-</td>
</tr>
<tr>
<td>14</td>
<td>3</td>
</tr>
<tr>
<td>13</td>
<td>8</td>
</tr>
<tr>
<td>3</td>
<td>-</td>
</tr>
<tr>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>9</td>
<td>2</td>
</tr>
<tr>
<td>8</td>
<td>2</td>
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<tr>
<td>7</td>
<td>3</td>
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<tr>
<td>5</td>
<td>1</td>
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<td>5</td>
<td>1</td>
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<tr>
<td>4</td>
<td>-</td>
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<tr>
<td>5</td>
<td>-</td>
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<tr>
<td>3</td>
<td>-</td>
</tr>
<tr>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>2</td>
<td>-</td>
</tr>
</tbody>
</table>

Wellington Hospital Board
Hospital Services
Community Health Services
Department of Social Welfare
A C C
Private Hospitals and Hospices
General Practitioners
Domiciliary Nursing Trust
Practice Nurses
Cancer Society
Church Groups
Clergy
Baptist Social Services
Catholic Social Services
Methodist Social Services
Presbyterian Social Services
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Mothers Helpers
Samaritans
Good Samaritans
Red Cross
St John's Ambulance
Old People's Welfare Council
Maori Women's Welfare League
British Sailors Society
Care and Craft
Under Stress
CONCLUSIONS OF QUESTION 6

The most common needs arising were in practical areas such as help required with lifting the patient, cooking meals, and generally running the household.

Counselling, in that the relatives liked to talk to knowledgeable people about what was going on in their lives, was the second most common need, and this was followed by the need for good family support.

The Community Health Services division of the Wellington Hospital Board was most commonly used, and the District Nurse sub-division of this made for the great majority of its use.

32 contacts with the various services left the people with an impression of very satisfactory to excellent standards of help, two contacts satisfactory, and only one contact was unsatisfactory, a very encouraging comment for all those services concerned.

The source of knowledge about the services used was mainly from the GPs followed closely by hospital or hospice staff. Both the GPs and hospital/hospice staff had little knowledge of the complete range of services available, and also could not put the relatives on to any one agency that had all this knowledge. This seemed to be the main reason for under use of the services available to the terminally ill, and therefore non-fulfillment of needs. Similarly, although the people themselves knew the names of a lot of the organisations offering services, they did not realise these organisations could offer help to terminally ill people.

The other thing that came out of this question was that people could not really see all of their needs, even now with the benefit of hindsight, in that they put up with unnecessary stress. This suggests, therefore, that one group should go into the home situation of the terminally ill person and actively look for such stresses in the family, and volunteer what services are available to relieve these.

7. Do you feel able to tell me about your death? (Were you able to be there?)

Question 7 was in order to find out about the actual circumstances surrounding the death, and the feelings about these.

<table>
<thead>
<tr>
<th>PLACE OF DEATH</th>
<th>NUMBER</th>
</tr>
</thead>
<tbody>
<tr>
<td>HOSPITAL</td>
<td>13</td>
</tr>
<tr>
<td>HOME</td>
<td>5</td>
</tr>
<tr>
<td>HOSPICE</td>
<td>4</td>
</tr>
<tr>
<td>OTHER:</td>
<td></td>
</tr>
<tr>
<td>Home of Compassion</td>
<td>1</td>
</tr>
<tr>
<td>Aroha Home</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>TIME SPENT AT PLACE OF DEATH</th>
<th>NO.</th>
</tr>
</thead>
<tbody>
<tr>
<td>LIFETIME (AT HOME)</td>
<td>3</td>
</tr>
<tr>
<td>UNKNOWN</td>
<td>6</td>
</tr>
<tr>
<td>HOURS ONLY</td>
<td>1</td>
</tr>
<tr>
<td>1 - 6 DAYS</td>
<td>4</td>
</tr>
<tr>
<td>1 - 3 WEEKS</td>
<td>4</td>
</tr>
<tr>
<td>1 - 9 MONTHS</td>
<td>5</td>
</tr>
<tr>
<td>6 YEARS</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>PERSONS PRESENT AT TIME OF DEATH</th>
<th>NO.</th>
</tr>
</thead>
<tbody>
<tr>
<td>NO-ONE</td>
<td>4</td>
</tr>
<tr>
<td>NEXT OF KIN</td>
<td>6</td>
</tr>
<tr>
<td>FAMILY</td>
<td>7</td>
</tr>
<tr>
<td>HOSPITAL STAFF</td>
<td>9</td>
</tr>
<tr>
<td>OTHER: PRIEST</td>
<td>1</td>
</tr>
<tr>
<td>FRIENDS</td>
<td>1</td>
</tr>
</tbody>
</table>
Comments made by interviewees:

(1) **Hospice deaths** - 4 cases

- 4 said visiting hours good
- 3 had to leave before patient died (to do something else)

(2) **Hospital deaths** - 13 cases

- 3 pleased with access
- 3 were not able to be present when patient died (one of these praised the hospital chaplain)
- 2 were pleased with all aspects of care
- 5 made no relevant comments

(3) **Home deaths** - 5 cases

- 2 preferred not to have hospital death
- 2 commented death peaceful, painless
- 1 made no comment

(4) **Home of Compassion death**

Contact adamantly preferred not to have hospital death - specifically mentioned visiting hours, humanity, privacy and general noise level as considerations.

If everything had been ideal, would you have changed anything?

(1) None had ardent suggestions for change of those whose relative died at hospital or in a hospice.

(2) Of home deaths, in one case patient's preference was a hospice but family preferred to care for her at home.

(3) Regarding the patient who died in the Home of Compassion, contact said "Couldn't have been a better place".

8. Is there anything else you would like to say, which you think is important to you, or that we should know?

Question 8 was in order to give opportunity for interviewee to express anything yet unsaid and also to allow rounding off of interview.

However, nine declined to comment.

4 expressed need for more realistic communication from medical personnel to dying patients and kin, (or to give kin option of informing patient), and not to use concepts of "next of kin" as excuse for avoiding questions by other family members.

Others not recorded were heterogeneous but basically expressing satisfaction with overall terminal care.
DISCUSSION

1. THE DEFINITION

It can be seen from the preceding description that the retrospective definition of any patient as "terminally ill" is fraught with difficulties.

In our study we erred towards over-inclusion rather than under-inclusion when collecting our "provisionally" terminally ill population.

We agreed that a study such as ours should identify all those for whom care designed for terminal illnesses would be appropriate, and we wished to avoid the mistake of identifying only the unambiguous cases such as cancer patients for whom adequate provision may have already been made, on the basis of previous research.

Because of our over-inclusive bias, we were forced to re-assess our "provisionally included" population.

The definition we are given states clearly that a terminally ill patient is expected to die within 12 months. The implication seems to be that this expectation refers to the medical professionals involved with the patient's management, and that the former are in agreement.

We asked general practitioners whether they "had expected (their patients) to die from a progressive, incurable illness within twelve months". Most were unhappy with the question, especially in cases of congestive heart failure, chronic bronchitis, or emphysema. Many admitted that they had expected death to occur at any time within the last five to ten years, but were not prepared to be more precise.

These doctors heard the definition only once. Our telephone calls inevitably interrupted their practices to some extent, and caught them unawares in most cases. There was thus usually no opportunity for a detailed consideration of our questions, before responding to them. We should note also that by excluding deceased patients from our sample, doctors were not obliged to give or refuse permission for us to contact their relatives. Further, a retrospective confirmation of an "expectation of death" may not correspond accurately with the actual ante-mortem expectation.

At this stage, we should like to present the comments of Dr McHaffie and Dr Holst, noted Wellington specialists in the fields of respiratory and cardiac clinical medicine respectively.

Referring to the definition, Dr McHaffie felt that only a very small percentage of patients with congestive heart failure were terminally ill - perhaps two per month in the Cardiology Ward at Wellington Public Hospital. The presence of resistant heart failure treated by Captoril, Prazosin or Hydralazine, or Frusemide (160 mg/day or more) would suggest that a patient was terminally ill. The majority of patients with a cardiomyopathy, on the other hand, could be defined as terminally ill at some point of their course. Irreversible ventricular failure was also associated with poor prognosis.

However, the majority of patients suffering from "functional cardiac insufficiency" although crippled by shortness of breath and eligible for special services - would not seem to be terminally ill.

Dr Holst stated that the medical expectation required to define an emphysematous or chronic bronchitis case as terminally ill would almost never be justified. The acute exacerbation leading to death was not sufficiently predictable.

He was able to list factors which indicate a poor prognosis: homozygous antitripsin deficiency (rare); FEV < 25% predicted or < 1.0 litres; resting tachycardia; weight loss; increased pulmonary vascular resistance and right ventricular failure. These factors are not sufficient justification for defining the illness as terminal.
2. A PROSPECTIVE STUDY OF THE TERMINALLY ILL

The major methodological problem we foresee in such a study is identification of the terminally ill population. If a clear definition of terminal illness were stated, perhaps a register of all patients suffering from such an illness could be kept in the future.

However, a prospective study of such aspects as services used, disclosure of information and medical management during a terminal illness also raises ethical problems. We doubt that a proper non-intrusive research design would be possible, or ethically justified.

3. ACCURATE RETROSPECTIVE DATA

We regret that constraints of time and manpower discouraged us from taking a large sample of all the 1980 Certificates of Death, and analysing these intensively via hospital records, general practitioners and surviving relatives, thereby making an informed statement as to the presence or absence of a terminal illness in all cases. We would thus have presented an accurate perspective on the population who die within any one year, with respect to the likelihood of terminal illness within all disease groupings.

Unfortunately, our analysis of atherosclerotic, central nervous system and degenerative disease is particularly inadequate.

We would draw the attention of future research workers to the cross-checked and readily accessible statistical data compiled by the National Health Statistics Centre. This resource would have been ideal for our purposes, had the 1980 statistics been available; we stress that this wealth of accurate information would be of tremendous benefit to anyone in providing health services for terminal illness.

We have seen our project as a pilot study of an important, delicate and complex area of Health Care, and would take this opportunity to encourage others to share this perspective.

ACKNOWLEDGEMENTS

We have not produced this study without the practical help, advice and moral support of many people.

We are particularly indebted to:

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David McNaffie
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Professor Johnson
Mrs Hawkesworth
Margaret Storm
Gail de Boer
Staff of Hutt and Wellington Hospital Medical Records
General Practitioners

and all those who shared their experience of terminal illness with us and we thank them sincerely for their time and sympathy.
TITLE: TERMINAL ILLNESS IN WELLINGTON

CLIENT: WELSAC (Working Party on the Terminally Ill, Wellington Health Services Advisory Committee)

PREAMBLE:

The Care of the Terminally Ill has certain qualities which make it different from some other facets of health care. Not only is such care the concern of hospitals but it also frequently involves Private or Voluntary institutions such as Hospices, General Practitioners, Community Health and Oncology Nurses; societies such as the Cancer Society, Religious and other organisations, individual consumers and consumer groups. All of these must, in some way, fit together in different patterns in different circumstances.

The Wellington Health Services Advisory Committee has recently formed a working group to consider the question. This working group has proposed a definition which it intends to use, but has difficulty in proceeding further without some quantitative data upon the nature and extent of the population which falls into this category in Wellington.

THE DEFINITION:

"Any progressive illness from which the patient is expected to die and in which there is no further prospect of curative treatment. A terminally ill person is one who suffers from a Terminal Illness and whose life expectancy would normally be of less than twelve months during which time access to special services may be required."

PROBLEM OBJECTIVES:

1. How many persons in a recent year in Wellington could be said to fall into the definition given?

2. What are some of their qualities? (eg. age, sex, diagnostic category, location).

3. Which services did they use? Can the type of assistance received from each service be categorised and/or qualified?

4. To what person or group outside the immediate family did they first turn for support and advice? When did this occur?
Dear

My name is I am a medical student at the Wellington Hospital Clinical School of Medicine. The Wellington Health Services Advisory Committee Working Party on the Terminally Ill has asked a group of my colleagues to conduct a research project on their behalf. We hope that you will consent to take part in this research.

Many of us are concerned that we do not understand the problems which terminally ill people and their relatives face. We understand that you have recently undergone such an experience and feel that only by talking with people such as yourself can we come closer to a real understanding of terminal illness, and to a critical evaluation of the services which the Health Department provides.

We realise that it will be difficult for you to share your experience with us, but hope that you will feel able to do so. The Committee believes that this project will be of great value in supporting people in this situation in the future.

With your permission, I should like to visit you at your house for an hour or two. I shall telephone to arrange a time for the interview. This would take place between now and 10 June 1981, on a date convenient for you.

Thank you for your kindness.

Yours sincerely

Medical Student (5th Year)
Dept. of Community Health
APPENDIX C

QUESTIONNAIRE

My name is and I am the Medical Student who rang you about the letter I sent, and arranged to come and see you to talk with you about last illness.

While we talk I'll be noting things down. This information will be used to try and improve the services available to other people who are facing the same sorts of problems. You are welcome to read this at the end, if you wish.

We are interested not only in these answers, but in anything else you consider important or want to discuss. The information obtained will be presented in such a way that there will be no way of identifying the names and addresses of people.

1. What is your relationship to ?
   Father [ ] Mother [ ] Husband [ ] Wife [ ]
   Son [ ] Daughter [ ] Sibling [ ] Other [ ] (specify)

2. Who else is in the family? ("I know little about you", etc.)

3. How long was your ill, such that he/she was unable to continue to lead his/her normal life?
   Time: ____________________________
   Where was he/she at this time?

4. Could you tell me something about how you and your found out that he/she didn't have very long to live?
   Not told [ ] [ ] GO TO SECTION C
   Time before death: ____________________________
   Place told: ____________________________

Information from:
1) GP [ ] Comments: [ ]
2) Hospital Doctor [ ]
3) Minister of Religion [ ]
4) Nursing Staff [ ]
5) Other (specify) [ ]

Information to:
1) Patient only [ ] Next of Kin told? [ ] [ ] [ ] GO TO SECTION A
   Who told N of K?

2) Next of Kin only [ ] Patient told? [ ] [ ] [ ] GO TO SECTION A
   Who told Patient?

3) Patient and Next of Kin together? [ ] GO TO SECTION B

4) Next of Kin only [ ] Patient told? [ ] [ ] [ ] GO TO SECTION A
   Who told Patient?

Comments:
SECTION A

How do you feel about this?  

(NB. if family decided not to tell patient or if patient decided not to tell family, NOTE HERE)

GO TO SECTION B

SECTION B

How do you feel about the way you were told?  

(ie about the way, the time, the place, the person who told you, whether alone together, etc.)

GO TO SECTION D

SECTION C

How do you feel about not being told?

Information:

1) Assumed & guessed by patient?  □  
2) Requested by Patient □  What happened?  
3) Assumed & guessed by Next of Kin? □  
4) Requested by Next of Kin □  What happened?  
5) Neither assumed nor requested □  

Comment:

SECTION D

If you could have had everything perfectly handled, how would you have liked to have been told?  

(ie about the way, the time, the place, the person who told you, whether alone, together, etc.)

5. As well as talking specifically about how seriously ill your was, families often feel they need to know what to expect during the illness and of the treatments. Can you tell me about any talks like that you had with anybody?

a) Medical person offered to discuss illness, treatment outcome □  
   Who gave it and when did it occur?

b) No offer was made. □  
   How do you feel about this?
   Patient and/or next of kin actively sought out advice □  
   What happened?
   Patient and/or next of kin did not seek out advice □  
   Why not?

Comments:

What sort of treatment did he/she have?
How much pain did you have?

None
very little
reasonable
quite severe
very severe

How adequate was pain relief?

Totally inadequate
Inadequate
Adequate
Very Good
Excellent

What was the medicine given?

What group(s) outside the immediate family did you first go to, to meet these needs?

Agency
Help Given was:
Totally unsatisfactory
Unsatisfactory
Satisfactory
Very Satisfactory
Excellent

Time occurred - in relation to known prognosis/illness

How learned of these groups:

Did you use any further group(s) later on?

NO
YES

Agency:
Help given was:
Totally unsatisfactory
Unsatisfactory
Satisfactory
Very Satisfactory
Excellent

How learned of these groups:

Comments:

6. When someone is very ill they and their family often find that they have special needs, for example, they may have financial difficulties, they may need help with cooking and laundry, they may need someone to talk to.

Could you tell me something about any needs that you felt you and your had during those last months?
Did you know of any of these groups who can provide assistance with terminal illness?

(Hand over list)

Tick those known
Did you use any of them?  Cross those used.

Comments:

7. Do you feel able to tell me about your death?

(Were you able to be there?)

Where did die?
At home  At hospital
At hospice  Other [Specify]

Died:
Alone  with Next of Kin
with Family  with Hospital staff
Other [Specify]

Comments:

When did go there?

If everything had been ideal, would you have changed anything?

8. Is there anything else you would like to say, which you think is important to you, or that we should know?

Thank you very much. What you have told me will be very helpful to us, and I hope talking about this has been of some benefit to you. If you would like to contact me for any reason, my telephone number is
Wellington Hospital Board
Hospital Services
Community Health Services
Department of Social Welfare
ACC
Private Hospitals and Hospices
General Practitioners
Domiciliary Nursing Trust
Practice Nurses
Cancer Society
Church Groups
Clergy
Baptist Social Services
Catholic Social Services
Methodist Social Services
Presbyterian Social Services
Salvation Army Social Services
Wellington City Mission
NZ Council for Christian Social Services
St Vincent de Paul Guild
Jewish Care of the Aged

Community Centres, Resource Centres or Health Centres
Brooklyn
Kilbirnie
Newtown

Bereaved Parents Group
Widows and Widowers Association
Citizens Advice Bureau
Mothers Helpers
Samaritans
Good Samaritans
Red Cross
St John's Ambulance
Old People's Welfare Council
Maori Women's Welfare League
British Sailors Society
Care and Craft
Under Stress
APPENDIX III

DESCRIPTION OF PHYSICAL, EMOTIONAL, SPIRITUAL, FINANCIAL, AND DOMESTIC PROBLEMS ENCOUNTERED BY THE TERMINALLY ILL PATIENT AND HIS FAMILY

PHYSICAL PROBLEMS ENCOUNTERED
BY THE TERMINALLY ILL AND THEIR FAMILIES

There is evidence that the problems encountered by people dying with advanced cancer differ from those of people dying with other diseases.

1. Terminal cancer

The figures quoted below are those from the St. Christopher's In-Patient Unit, London, St. Columba's Home Care Service, Edinburgh, and the Mary Potter Hospice, Wellington. These patients form a selected population, and no overall estimate of the incidence of symptom problems in the entire group of patients with terminal cancer can be made. There are also dangers in translating such figures from one country to another.

2. Terminal illness other than cancer

As far as we are aware there are no figures for physical problems encountered by terminally ill patients with non-neoplastic conditions.

INCIDENCE OF PHYSICAL PROBLEMS
OF IN-PATIENTS WITH ADVANCED CANCER

<table>
<thead>
<tr>
<th>Symptoms</th>
<th>St. Christopher's Hospice In Patients (%)</th>
<th>St. Columba's Home Care Service (%)</th>
<th>Mary Potter Hospice Wellington (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>66</td>
<td>74</td>
<td>80</td>
</tr>
<tr>
<td>Anorexia</td>
<td>61</td>
<td>61</td>
<td>-</td>
</tr>
<tr>
<td>Weight loss</td>
<td>59</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Cough</td>
<td>48</td>
<td>31</td>
<td>-</td>
</tr>
<tr>
<td>Depression</td>
<td>-</td>
<td>46</td>
<td>-</td>
</tr>
<tr>
<td>Constipation</td>
<td>45</td>
<td>57</td>
<td>-</td>
</tr>
<tr>
<td>Dyspnoea</td>
<td>41</td>
<td>31</td>
<td>13</td>
</tr>
<tr>
<td>Nausea and/or vomiting</td>
<td>41</td>
<td>25</td>
<td>27</td>
</tr>
<tr>
<td>Effusion and/or oedema</td>
<td>26</td>
<td>-</td>
<td>24</td>
</tr>
<tr>
<td>Insomnia</td>
<td>24</td>
<td>12</td>
<td>-</td>
</tr>
<tr>
<td>Pressure sores</td>
<td>22</td>
<td>14</td>
<td>-</td>
</tr>
<tr>
<td>Weakness</td>
<td>21</td>
<td>-</td>
<td>20</td>
</tr>
<tr>
<td>Mental Confusion</td>
<td>-</td>
<td>20</td>
<td>10</td>
</tr>
<tr>
<td>Incontinence</td>
<td>20</td>
<td>20</td>
<td>-</td>
</tr>
<tr>
<td>Dysphagia</td>
<td>16</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Cachexia</td>
<td>12</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Drowsiness</td>
<td>10</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Haemorrhage</td>
<td>9</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Jaundice</td>
<td>7</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Stomas</td>
<td>7</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Paralysis</td>
<td>5</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>
In addition, more general physical problems such as reduced mobility may cause distress. We are able to find no data relating to the incidence of these problems, or their duration, in either terminally ill group.

EMOTIONAL PROBLEMS OF THE TERMINALLY ILL PATIENT AND HIS FAMILY

A death is a crisis, albeit a normal event, in a family and as such may cause problems both before it occurs and during a variable period post-mortem.

Denial )

Anger ) May be normal or abnormal, and in either case may cause a problem for the patient or the family group.

Bargaining )

Depression )

Fear: Fear is a natural reaction to the unknown and may therefore be compounded by lack of frankness on the part of the health professional, relative, or dying person himself. It may relate to a myriad of different unknowns - "What is it like to die? Will death be painful? Will there be a sudden haemorrhage?" The problem of fear may be compounded when its existence is denied, or its cause is displaced.

A sense of failure: The sense of a misspent part or whole of life is common and often realistic to the patient.

Unfinished business; for example, a persisting bad relationship, may cause considerable emotional problems.

Loss/grief: The grief of the family and the problems which it may cause, including high morbidity and mortality, are well recognised. Less well recognised is the patient's grief at a host of losses, for example, belongings, family, plans for the future, and body image.

Loneliness: Patients often feel isolated from normal social processes during their terminal illness (Ref.5).

The Health Professional: Many of the problems outlined above may be present also in the health professional and may considerably reduce the prospect of resolving patient/family group problems in all patients encountered by the affected professional.

Aggravating factors:

All these problems may be compounded if:

(a) Health professionals are less than honest with the patient.
Health professionals are not prepared to spend time with the patient/family group when it is needed.

The patient is not allowed to express his feelings, or these feelings (and he himself) are not accepted.

Suitable surroundings are not made available for health professionals to communicate in privacy and with dignity with the patient and family.

Unresolved emotional problems such as inadequate communication, during the patient's illness may leave residual problems with the patient's relatives after the patient's death.

SPIRITUAL PROBLEMS EXPERIENCED BY THE TERMINALLY ILL PATIENT AND HIS FAMILY

The problems experienced by such families depend upon their spiritual status at the time of onset of the terminal illness. Five spiritual groupings can be identified:

Religious well integrated person:

who has a healthy sense of his/her intrinsic worth (self love) coupled with a healthy (trusting) sense of his/her worth in God's eyes. The well integrated person has few spiritual problems - he feels safe.

Religious but poorly integrated person:

who has set great store by careful observance of religious duties - with attendance at church, reception of sacraments etc, but has little self love and therefore little trust in God's love. Such a person may have problems because he sees himself as unworthy and therefore views God with fear - more as a very exacting judge or policeman, rather than a loving Father.

Non-practicing believer:

who believes in God and his authority expressed through his particular church - who believes in the value of church-going etc, but through laziness or lack of organisation hasn't bothered. Such a person may have problems because he may feel he has failed God and that now it is too late to do anything about it. Consequently he/she may feel fearful that God will now ignore, blame or punish him.
Irreligious person:
who has a vague belief in there being "someone up there somewhere" but has never joined any church or religious group nor made any attempt to make contact with or acknowledge God in his/her life. This person may have problems, because now that all the things he used to depend on (health, possessions, and security) are slipping from his grasp and he may want to turn, almost as a last resort, to God but feels hypocritical in doing so.

Atheistic person:
who denies the existence of God, or soul, or after life. Such a person would seem to have no spiritual problems because he denies the spiritual world. However along with the religious but poorly integrated person, non-practicing believer, and irreligious person the patient may experience greater emotional problems than the religious well integrated person. An atheist may experience:

(a) Fear - of a painful or prolonged death.
(b) Grief - or sadness at being separated from this life, loved ones etc.
(c) Anger - that for him it must all end now, while others live on.
(d) Guilt - or regret that he hasn't spent the time better, more worthily.

The problems outlined above may persist, in relatives, after the person's death, albeit with a somewhat different emphasis - anxiety about the dead person's safety (is he in Heaven?) - fear of the death being retribution from God, etc. It should be noted that unresolved spiritual problems may develop into serious psychological or physical problems.

FINANCIAL COSTS OF A TERMINAL ILLNESS
TO THE PATIENT AND FAMILY GROUP
The financial costs will obviously vary with such factors as where they live, length of terminal illness, and the degree of debility. In addition there are likely to be considerable differences amongst the self employed, employed, unemployed, and retired. Costs will also depend on whether the patient is the principle earner or non-earner.

1. Loss of income during life: This is unlikely to be a significant cost for those entirely dependent on retirement or unemployment benefits. The employed are usually granted extended sick leave, whether they are the carer or patient, and many families have accrued sufficient leave to carry them over the terminal illness. The self employed, however, may suffer considerable hardship.
2. **Additional Costs to the Family**: To assess the true economic loss to a patient's family, consideration should also be given to duties performed by that person in the family setting. For example, it may prove necessary to employ a paid housekeeper or gardener.

3. **Travel**: The cost of travel to surgeries or out-patient clinics may be considerable — particularly when a patient is being "followed up" by as many as six different doctors. Travel costs may also be high for relatives coming from a distance to visit the dying person.

4. **Drugs** prescribed, but not on the the Department of Health's Free list.

5. **Comfort Items**: Many families will purchase lazy boy chairs, special pillows, inflatable rings, ripple mattresses, sheepskins or any other item which they feel will contribute to the patient's comfort.

6. **Doctors' fees**

7. **Hospital or Hospice fees** for those cared for in fee charging institutions.

8. **Miscellaneous costs** e.g. additional laundry, special foods etc.

9. **Funeral expenses**: An inexpensive funeral in New Zealand is $1,000 to $1,200.

10. **Illness during the bereavement**: Grief carries a high morbidity, and even a mortality, both of which may impose additional financial costs on the family.

11. **Continuing loss of income**: If the person who dies is the principal earner, the family will continue to suffer a degree of financial hardship.

12. **Additional legal costs**: May be incurred if the patient is ignorant of his prognosis and fails to make appropriate arrangements.

**Note**: This study group does not have adequate data to quantify these costs, which, in the case of some families, may be considerable and significantly add to the physical and psychological burdens of a terminal illness.

**BENEFITS**

State and private insurance benefits offset some of the financial costs of terminal illness. (See Appendix V for a list of benefits available from the Department of Social Welfare, and Appendix VI for the financial assistance and services available from the Wellington Hospital Board).
DOMESTIC AND SOCIAL PROBLEMS ENCOUNTERED
BY THE TERMINALLY ILL PATIENT AND HIS FAMILY

1. Food and food preparation: The patient's food preferences may alter during the terminal phase. The provision of poorly prepared, unattractive meals may exacerbate this. If the housewife is ill, this problem may be compounded. In addition, many people genuinely resent the presence of another man or woman in their kitchen.

2. Housekeeping: may present an obvious practical problem if the housewife becomes physically unable to perform such tasks.

3. Bathing and cleanliness

4. The layout of the home may be far from optimal for the care of the dying. There may be no available separate bedroom, a lack of supportive fixtures, steps or stairs, small toilet area, narrow passages, and doorways which are unsuitable for wheelchairs.

5. Children are important to the terminally ill although they are often excluded from contact with a dying parent or grandparent.

6. Social contact with friends or more distant relatives may be reduced beyond the wishes of the dying individual. This may result from (usually) unjustified fears in visitors. 40% of patients in a recent study actively complained of being lonely - or having no one to whom they could really turn (Ref.5). Alternatively, there may be excessive, but usually superficial, social contact.

Dr P.R.G. Turnbull,
Convenor of the Sub-committee
APPENDIX IV

QUESTIONNAIRE

1. DO YOU PROVIDE A SERVICE FOR THE TERMINALLY ILL?
2. WHAT SPECIFIC SERVICES DO YOU PROVIDE?
3. WHO IS ELIGIBLE TO RECEIVE THESE SERVICES?
4. IS YOUR SERVICE UTILISED EFFECTIVELY?
5. IF NOT WHY DO YOU THINK THIS IS SO?
6. HOW DO YOU THINK THAT BETTER UTILISATION COULD BE BROUGHT ABOUT?
7. WHAT DO YOU DO IF YOU GET A REQUEST FOR HELP FROM A FAMILY WHERE THERE IS TERMINAL ILLNESS?

Mr H.R. Evans,
Convenor
APPENDIX V

STATUTORY AGENCIES

1. THE DEPARTMENT OF SOCIAL WELFARE

Various benefits which may be of assistance to the terminally ill and their families can be applied for from the Department of Social Welfare:

(a) Sickness Benefit
(b) Invalids' Benefit and Miners' Benefit
(c) Disability Allowance
(d) Handicapped Child's Allowance
(e) Assistance for families caring for the seriously disabled
(f) Domestic Purposes Benefit for the Care at Home of the Sick or Infirm
(g) Emergency Maintenance Allowance
(h) Unemployment Benefit
(i) Widows' Benefits
(j) Benefit on Death
(j) National Superannuation (13 weeks post-mortem benefit)

Additional benefits

An additional benefit is available to beneficiaries whose income and cash assets are limited and who are paying relatively high accommodation costs.

An allowance is available to disabled persons to assist with the additional expenses caused through their disability. These expenses could include special diets, special clothing, and transport costs. This allowance can only be paid after beneficiaries have been in receipt of a sickness benefit for at least twenty-six weeks.

If the benefit is likely to continue for longer than twenty-six weeks beneficiaries may be entitled to a telephone rental concession equal to one-half of the amount of their rental.

A home-help service is available for beneficiaries who need assistance in the home. All or part of the costs of employing help may, if necessary, be met by the Department of Social Welfare.
1. SERVICES PROVIDED

The Wellington Hospital Board provides a wide range of services for the terminally ill patient and his family. These cover the following areas:

(a) Hospital based medical assessment and treatment services.
(b) In-patient, day patient, and out-patient clinic services.
(c) Nursing services, both hospital and community-based.
(d) Para-medical services, both hospital and community-based.
(e) Chaplaincy services of all denominations.
(f) Home support services.
(g) Supplementary finance.

Terminally ill patients and their families are eligible for all of the appropriate services listed above.

2. REASONS FOR INEFFECTIVE UTILISATION

In the majority of cases the services are used effectively. However, despite the in-depth services provided, there is a lack of awareness, knowledge, and understanding of what is available which sometimes leads to ineffective utilisation.

There is inadequate referral to the Community Health Nursing Service by some nursing and medical personnel, both in hospital and in the community. This is sometimes related to medical resistance, possibly because the service is seen as usurping other medical roles. It may also be related to lack of organisation and feed-back between hospital board, medical personnel and general practitioners.

Sometimes appropriate care is not given owing to lack of resources, or lack of training in the care of the terminally ill, and in some instances this may be due to an apparent lack of co-operation and interest in this particular area.

There is some lack of appropriate physical resources required for the service.

There are inadequate nurse-to-patient ratios to allow the quality of service desired.

There is some instability of hospital nursing staff because of hospital based nursing programmes.
3. SUGGESTIONS FOR IMPROVED UTILISATION

(a) There is a need for better public education and awareness of the services available:

(b) Co-ordination of medical services, particularly between hospital, clinic, and general practitioners.

(c) On-going education for nursing, medical, and paramedical personnel.

(d) Provision of the resources required to provide an effective service.

(e) Use of appropriately qualified personnel, and phasing-out of the hospital-based nursing programme.

(f) Development of an experienced multi-disciplinary team for advice and consultation on terminal care.

(g) Appointment of a small group to make recommendations relating to terminal care, particularly its co-ordination.

Hospital Boards should be taking the lead in this field.

Miss P. MacInnes
APPENDIX VII

VOLUNTARY AGENCIES

ACTIVE SUPPORT

1. WELLINGTON DIVISION OF THE CANCER SOCIETY
OF NEW ZEALAND

The Cancer Society provides the following services in the Wellington Region:

(a) Provision of night nurses;
(b) Transportation services;
(c) Financial assistance;
(d) Telephone counselling and information service.

The society is aware of the need for an information service, and has attempted to meet the need by providing a telephone counselling service staffed by the Community Health Nursing Service. The nature of the enquiries are various and include questions about diagnosis and symptoms, services available and general requests for information about cancer. Most of the enquiries have come from relatives. The service has been utilized reasonably well over the last six months, and about sixty calls have been received.

The Wellington Division of the Cancer Society of New Zealand has employed various methods to publicise the service. Even so, it appears that most people are not aware of the existence of the service until it is brought to their attention by some other agency.

2. MARY POTTER HOSPICE AND TE OMANGA HOSPICE

Two hospices provide a complete range of nursing, medical and counselling services. For a full description of the services available, see Appendix XII Mary Potter Hospice, and Appendix XIII Te Omanga Hospice.

LIMITED SUPPORT

Most church groups appear to provide mainly counselling and spiritual support to the patient and family. In most churches the support of terminally ill patients and their families is an important part of the pastoral duties of the priest or minister. Most place great importance on the role of the hospital chaplain. Some do provide some form of family assistance, such as preparing meals, and looking after children. No church, however, appears to have a formal policy on the care of terminally ill patients and their families, and church authorities have only limited knowledge of the services available.
A personal approach has been made to the following voluntary agencies:

1. THE ANGLICAN CHURCH

Services include the Russell Kemp Hospital. The church has no formal policy in respect of the care of the terminally ill. Each vicar is expected to become involved with any of his parishioners where either the person or somebody in the family is so affected. This is treated as a very important part of the pastoral duties of the vicar, and involves both the counselling of the family and help to the patient during their period of terminal illness. The church recognises that the period after the death of the patient is a very difficult period for the family, and as a result the vicar does pay close supervision of the needs of the family. These were the views expressed by Bishop Norman.

2. THE CATHOLIC CHURCH

The Catholic Church provides the following services:

(a) **Home of Compassion** (In-patient care)

(b) **Mary Potter Hospice**  
(Specifically for terminally ill patients)

(c) **Home nursing of patients** and caring for the family, preparing meals, and looking after the children.

(d) **Little Sisters of the Assumption**

Note: The Sisters work in conjunction with the Community Health Nursing Service and with the Community Domiciliary Nursing Trust. Religious Sisters from other congregations, for example, Good Shepherd Sisters and Sisters of Mercy, also help with this type of care.

(e) **Family Support**

   (i) Religious Orders of Sisters throughout the Archdiocese.
   (ii) Catholic Social Services.
   (iii) St. Vincent de Paul Society.
   (iv) Catholic Women's League.
   (v) Parish support through parish priests, and social welfare committees of parish pastoral councils.

(f) **Pastoral Support**

Full-time chaplains in public hospitals.
3. **METHODIST CHURCH**

The church provides the services of the Wesleyhaven Eventide Homes. There exists a policy similar to that of other denominations, whereby pastoral care and part-time chaplains in some hospitals are provided. This information was supplied by Rev. Hanson, Chairman, Wellington Methodist District.

4. **SALVATION ARMY**

The policy is basically that of other denominations except that counsellors are provided who liaise when the patient and family are receptive. Colonel Calaghan provided an account of services available.

5. **THE WELLINGTON PRESBYTERIAN SOCIAL SERVICES ASSOCIATION**

The association administers the Woburn Home and Hospital, and Homes for the Aged. It places great importance on the Chaplaincy Service, which is full-time in the Wellington and Porirua hospitals, and part-time in others. Chaplains are becoming increasingly important in giving comfort to patients who are dying and to their relatives. The services of the chaplains are available to any patient on request, irrespective of denomination. The Director, Mr Lake, also stated that referrals by their chaplains or social workers were made to chaplains of other denominations where applicable.

**RESTRICTED BY ORGANISATIONAL FUNCTION**

This group covers a number of voluntary agencies. By the nature of their objectives, the following organisations can only assist a select group of people:

1. **BEREAVED PARENTS' ASSOCIATION**

The organisation does not provide a service in respect to the terminally ill patient. It does, however, provide a service to bereaved parents, irrespective of age. Its usual policy is to communicate with parents after learning, usually by means of the newspapers, of the death of a son or daughter. They do not, however, make any approach to the patient or relatives prior to death. The association has been in existence for about four years. It feels it could provide a better service if it could obtain more publicity. The President of the Society, Mrs Prench, supplied this information.
2. CITIZENS' ADVICE BUREAX

The Aro Street Bureau was interviewed. The Citizens' Advice Bureaux are prepared to offer advice to families or patients. In the case of enquiries concerning cancer or terminal illness they would refer people to the Wellington Division of the Cancer Society of New Zealand, Mary Potter Hospice, or Te Omanga Hospice. The Bureaux could serve as a useful centre for the further dissemination of information.

3. NEW ZEALAND RETURNED SERVICES ASSOCIATION

The association provides welfare grants in the case of need. To qualify, persons need only be a returned serviceman or woman, and does not need to be a member of the association. In some cases financial support would be extended to the patient's immediate family. Travel costs to visit the patient may also be met.

4. NEW ZEALAND WIDOWS' AND WIDOWERS' ASSOCIATION

This association is not directly involved with the terminally ill, but provides services for the bereaved immediately after death and, in many instances, when stress or other problems occur later. Any request for assistance in cases of terminal illness are re-directed to other helping agencies.

Mr H.R. Evans,
Convenor of the Sub-committee
APPENDIX VIII

THE ROLE OF THE GENERAL PRACTITIONER

IN THE CARE OF THE TERMINALLY ILL

The general practitioner's role in the delivery of any type of health care is determined by the individual style and type of medical practice which varies greatly.

Some doctors form an intensely personal relationship with their patients and relate to them more as friends. Others feel that personal involvement with patients distorts clinical judgement, and therefore they prefer to remain aloof and dispassionate, in the belief that objective medical advice can be better given in this way. Similarly, some doctors have a particular aptitude for one field of medicine, for example paediatrics or geriatrics.

Unfortunately, until terminal illness touches a family they may have little or no knowledge of which facilities are available, and, in particular, there may be no appreciation of the help that can be forthcoming from the general practitioner.

Although a general practitioner may be unable to participate directly by providing necessary treatment or counselling, he or she has a responsibility to see that appropriate care and attention is provided by some other agency.

General practitioners often work in a team relationship within their practices, and in a complementary role with the community health nurses. This is invaluable in providing after hours services, and services on a daily basis if and when required.

General practitioners' records should be the common repository for all information concerning their patients. Ideally, when the patient is attended by another doctor, information should be sent to the general practitioner who would then be in the unique position of having all information concerning the patient, and having an overview of the needs of the family.

There is a need for improved communication between hospital, hospice and community-based services. General practitioners should be aware of the latest therapeutic possibilities in treating the symptoms of the terminally ill.

Dr J.D. Bonifant
APPENDIX IX

DEFINITION OF A HOSPICE

The following definition of a hospice is that devised by the International Work Group on Death, Dying and Bereavement (1979), and the North American National Hospice Organisation (1979) (Ref.1).

"A hospice is a centrally administered programme of palliative and supportive services which provides physical, psychological, social, and spiritual care for dying persons and their families. Services are provided by a medically supervised inter-disciplinary team of professionals and volunteers. Hospice services are available in both the home and an in-patient setting. Home care is provided on a part-time, intermittent, regularly scheduled, and around-the-clock on-call basis. Bereavement services are available to the family. Admission to a Hospice programme of care is on the basis of patient and family need".
**APPENDIX X**

**MARY POTTER HOSPICE, WELLINGTON**

**INCOME AND EXPENDITURE FOR 12 MONTHS ENDED 31 MARCH 1981**

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of beds</td>
<td>21</td>
</tr>
<tr>
<td>Available beds</td>
<td>8,322</td>
</tr>
<tr>
<td>Occupied beds</td>
<td>7,411</td>
</tr>
<tr>
<td>Occupancy %</td>
<td>89%</td>
</tr>
</tbody>
</table>

**INCOME**

<table>
<thead>
<tr>
<th>Source</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paid by patient</td>
<td>51,946</td>
</tr>
<tr>
<td>Patient subsidy</td>
<td>47,959</td>
</tr>
<tr>
<td>TOTAL FEES PAID</td>
<td>$99,905</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Benefit</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>X-ray benefit</td>
<td>0</td>
</tr>
<tr>
<td>Surgical benefit</td>
<td>0</td>
</tr>
<tr>
<td>Medical benefit</td>
<td>34,195</td>
</tr>
<tr>
<td>Geriatric benefit</td>
<td>9,966</td>
</tr>
<tr>
<td>TOTAL BENEFIT</td>
<td>$127,161</td>
</tr>
</tbody>
</table>

| TOTAL INCOME                 | $227,066   |

**EXPENSES**

<table>
<thead>
<tr>
<th>Category</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Charge wages</td>
<td>214,713</td>
</tr>
<tr>
<td>Central supply</td>
<td>8,764</td>
</tr>
<tr>
<td>Nursing supervisor</td>
<td>14,105</td>
</tr>
<tr>
<td>Holiday pay</td>
<td>13,956</td>
</tr>
<tr>
<td>TOTAL DIRECT WAGES</td>
<td>$251,538</td>
</tr>
</tbody>
</table>

| OTHER WAGES                   | 76,535     |

| TOTAL WAGES                   | $328,073   |

<table>
<thead>
<tr>
<th>OTHER EXPENSES</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Crockery/linen</td>
<td>5,217</td>
</tr>
<tr>
<td>Food</td>
<td>27,094</td>
</tr>
<tr>
<td>Insurance/interest</td>
<td>6,112</td>
</tr>
<tr>
<td>Light, heat, power</td>
<td>16,678</td>
</tr>
<tr>
<td>Rates &amp; rents</td>
<td>6,293</td>
</tr>
<tr>
<td>Repairs &amp; maintenance (general)</td>
<td>25,299</td>
</tr>
<tr>
<td>Other costs</td>
<td>4,348</td>
</tr>
<tr>
<td>TOTAL CHARGE EXPENSES</td>
<td>$419,114</td>
</tr>
</tbody>
</table>

| NET LOSS                      | -$192,048  |

**CAPITAL EXPENSE**

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Renovations</td>
<td>99,670</td>
</tr>
<tr>
<td>Plant &amp; equipment</td>
<td>2,085</td>
</tr>
<tr>
<td>TOTAL CASH OUTFLOW</td>
<td>-$293,803</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>FINANCED BY:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Donations</td>
<td>* 177,718</td>
</tr>
<tr>
<td>Little Company of Mary</td>
<td>116,127</td>
</tr>
<tr>
<td>TOTAL FUNDS PROVIDED</td>
<td>$293,803</td>
</tr>
</tbody>
</table>

Annual Report, March 1981
APPENDIX XI

A COMPARISON OF STAFFING/WAGE COSTS

FOR THE MARY POTTER HOSPICE AND A GERIATRIC UNIT

The following figures show current staff/wage costs as at 15 February 1981, for a twenty-three bed hospice compared to a geriatric unit of similar size:

<table>
<thead>
<tr>
<th>Staff number/shift</th>
<th>$/fortnight</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Hospice</td>
</tr>
<tr>
<td>Staff number/shift</td>
<td>Difference</td>
</tr>
<tr>
<td>7.00-3.30 p.m.</td>
<td></td>
</tr>
<tr>
<td>Sister (LCM)</td>
<td>2</td>
</tr>
<tr>
<td>Reg. Nurse</td>
<td>3</td>
</tr>
<tr>
<td>Enrolled Nurse</td>
<td>1</td>
</tr>
<tr>
<td>Hospital Aide</td>
<td>3</td>
</tr>
<tr>
<td>TOTAL</td>
<td>9</td>
</tr>
<tr>
<td>3.00-10.30 p.m.</td>
<td></td>
</tr>
<tr>
<td>Reg. Nurse</td>
<td>1.5</td>
</tr>
<tr>
<td>Hospital Aide</td>
<td>2</td>
</tr>
<tr>
<td>TOTAL</td>
<td>3.5</td>
</tr>
<tr>
<td>10.00-7.00 a.m.</td>
<td></td>
</tr>
<tr>
<td>Reg. Nurse</td>
<td>2</td>
</tr>
<tr>
<td>Hospital Aide</td>
<td>1</td>
</tr>
<tr>
<td>TOTAL</td>
<td>3</td>
</tr>
<tr>
<td>GRAND TOTALS</td>
<td></td>
</tr>
<tr>
<td>$</td>
<td>9886</td>
</tr>
</tbody>
</table>

*DIFFERENCE IN SALARY COSTS PER ANNUM = $72,930

*The figures above are based on the staff/wage costs of a geriatric unit formerly run by Calvary Hospital, Wellington.

1. The relative nursing costs of running a hospice compared with a geriatric unit are clearly illustrated above. The costs reflect actual hours budgeted to work hours, at appropriate current rates of pay. One registered nurse on the night shift is a charge position.
2. The costs do not show any allowance for occupational therapy, nor do they reflect the assistance given by our volunteers. Trainees from the public sector are also excluded. For example, nursing students from Wellington Polytechnic, and medical students from the Wellington Clinical School of Medicine.

3. Non wage costs and domestics wage costs are expected to be similar under both units.

4. Notional Salaries for the Sisters of the Little Company of Mary, Calvary hospital, have been omitted, but would have to be accounted for if any lay person filled the position. Estimated additional costs are $2,270 per fortnight, or $59,020 per annum.

5. Realistic total running costs of Mary Potter Hospice for the year ended 31 March 1981:

\[
\text{\$419,114 + \$59,020 = \$478,134}
\]

6. When comparing the costs of a hospice to a geriatric unit of similar size, it should be noted that \$72,930 be deducted as additional hospice nursing/wage costs. The costs of a geriatric unit is therefore \$405,204. The difference in running costs of a hospice compared to a geriatric unit of similar size is 18%.

7. Wages are "at current costs". An increase of 13.75% (to equate with the public sector) has been agreed in Award negotiations to take effect from July 1981. This increase is not included in the above figures. For a further breakdown of income and expenditure of a hospice, see Appendix X.

Mr H.R. Evans
CANCER CARE

The development of a hospice for the continuing care of cancer patients

P. Davidson BSc MAPsS MNZPsS, Senior Lecturer, Acting Head, Department of Psychological Medicine, Wellington Clinical School,
H. R. Evans Chairman, Wellington Cancer Society,
A. J. Gray FRACP FFR, Radiotherapist and Oncologist; G. B. Kiddle FRACP, Medical Director;
Margaret Lancaster LCM, Sister in Charge; M. A. W. Shepherd MB BS MRNZCGP, Visiting Medical Practitioner, Mary Potter Hospice, Wellington

NZ Med J 1981; 93: 52-4

Introduction

There are approximately 5000 deaths from cancer in New Zealand each year, 20 percent of all deaths. Cancer is the second major cause of death in every decade from the age of five years on.1 Continuing care and terminal care of patients is thus a major health problem. Until recently nearly 60 percent of patients could expect to die in public hospitals, the remainder dying at home or in private hospitals, there are advantages and disadvantages of each of these systems of care.

For good home care of terminally ill patients, the following is desirable: (a) Patient—aware of his illness and able to co-operate with home care; (b) Family—collaborate well, and secure in the knowledge that help is available day or night; (c) Family doctor—available and willing, and skilled in the use of drugs for symptom relief; (d) Community health nurses—regular attendance, providing support to patient and family, backed by adequate local services; (e) Illness—not so prolonged as to exhaust the resources of the family.

In 1976, the community health nursing service at Wellington Hospital created the position of oncology nurse. This nurse visited cancer patients at home after leaving hospital, to assess how they and their family were adjusting to the patient’s illness. This rapidly developed into a specialised service for the care of terminally ill at home. The oncology nurse was able to call upon local community nurses to carry out day care, and night nurses, to enable the family to rest, were provided free by the Wellington Cancer Society. There are now three oncology nurses in the Wellington region. Patients are usually notified to them by ward sisters or attendant doctors.

Lichter and Davidson,2 emphasised that when patients and their families wish it, and the disease allows, home is the best place for the dying. Sometimes the burden of nursing may be too great to manage at home, even when considerable help is given through the various domiciliary services. At times the relatives may need a short break from the stress of caring for the dying person. With the changing

Reprinted from The New Zealand Medical Journal, July 22, 1981, No. 688, Pages: 52-4
pattern of symptoms in terminal illness, temporary admission may be needed to achieve control of a pressing problem. There is considerable evidence that a hospice environment provides the best care when patients cannot be managed at home.1

The move towards hospice care has been stimulated by two main concerns: (a) The isolation often experienced by terminal patients in hospital; (b) The high level of pain and other symptoms often associated with hospital and home care. Eighty percent of cancer patients will suffer physical distress during their terminal illness, and 60 percent will suffer pain. Parkes in a retrospective survey documented the pain experienced by patients with terminal cancer. Twenty-eight percent at home, 20 percent in a general hospital, and 8 percent in a hospice, suffered severe and unrelieved pain.2

Among the major impediments to good terminal care that have been identified are lack of knowledge of the therapeutic possibilities and the inability of staff to deal comfortably with the dying person. Selected and motivated staff with specialised training are essential for excellence in terminal care. So too, is a special place which exists solely to meet the unique needs of the patient.3

Background
Since 1975, the Sisters of the Little Company of Mary, whose vocation especially embodies the care of the dying, has developed with other interested people and the Wellington Cancer Society, the Mary Potter Hospice, to care for patients with terminal illness, 95 percent of whom have cancer. The hospice, the first of its kind in New Zealand, was officially opened in June 1979 by the Minister of Health.

Function of the hospice
Organisation. It is a programme of co-ordinated out- and inpatient services, primarily concerned in maintaining the patient at home, but with backup inpatient services when necessary. A symptom control clinic is held weekly for outpatients, and there is extensive co-operation with the community health nursing service and the department of radiotherapy and oncology of the Wellington Hospital Board. Total patient care includes caring for the family and other significant patient relationships. To this end, there is a minimum of regulations. Visiting is allowed at all times, relatives are encouraged to assist with the care of the patient, and can be accommodated in a self-contained flatette within the ward. Volunteer drivers provide transport for relatives, or for patients to clinics or occupational therapy.

Symptom control. Physical distress is any symptom that requires treatment. Pain is the commonest as documented by Parkes.4 In 1979, 81 percent of patients had pain present on admission. Good or fair pain control was achieved in all except 4 percent. Figure 1 shows the commonest symptoms experienced by patients admitted to the hospice.

Emotional problems. Patients and family require help to cope with the upheaval which accompanies impending death. While anxiolytics and anti-depressants have their place, their use is not as widespread as might be expected. Frequent communication by all staff involved with the patient and family, supports and helps them come to terms with their illness. A hospice can provide the informal environment, the high staff to patient ratio, and the specifically motivated and trained staff to cater for the total needs of all concerned.

Spiritual. In the provision of total care, attention must be given to spiritual as well as psychological and physical welfare. Clergymen from all denominations visit. Several times a year, multi-denominational services are held in the convent chapel during which those who have died are remembered. While pastoral care is an essential ingredient of total care, patients are never forced into a religious situation.

Inter-disciplinary care. All health care is provided under the direction of a medical practitioner. The director is a physician, supported by two visiting general practitioners and one visiting oncologist. There are 10 whole time equivalent nursing staff, two community nurses and nine nurse aides, a full time social worker, a visiting occupational therapist, physiotherapist, and clinical psychologist. Liaison occurs with the three oncology specialist nurses and the Wellington Hospital pharmacy.

Trained volunteers. Volunteers are specially selected and trained, they work in the hospice and in patients' homes, and provide services other than clinical. These activities facilitate listening and befriending.

Hospice facilities. The hospice has 23 beds, and includes an occupational therapy unit provided by the Wellington Cancer Soci-
ty, the J. R. McKenzie Trust, and the J. Sutherland Trust. The Wellington North Rotary Club provided a self-contained flatette for relatives. A cobalt unit for palliative therapy is attached to the unit.

Staff support and communication. Regular meetings are held with staff to discuss their concerns, to channel discussion, and to provide support and mutual evaluation.

Bereavement follow-up. In the 12 months following bereavement, studies have shown the mortality rate of the remaining spouse is significantly higher than normal. A post-bereavement visit is made to the surviving spouse or family by the oncology nurse and repeated as necessary.

General services available to the community. The general practitioner is the primary physician for the patient in the community, and has back up by the community health nurses. Hospice services are available on a 24 hour basis.

Teaching. The hospice has developed an active training programme: (a) Medical—All fourth year medical students at Wellington Clinical School interview a terminally ill patient in the hospice, and provide a written account of this interview. One hundred and forty students utilised this service in 1979 and 1980; (b) Nursing—Wellington Polytechnic nursing students spend three days a week for four weeks in the unit as part of their training; (c) An in-service education programme is held fortnightly, as well as a support group for the hospice staff; (d) In conjunction with Te Omanga Hospice a continuing care nurses’ training programme has been established.

Services based on need. The hospice is a non-profit making organisation, and its services are based on need rather than ability to pay. Patients undergo a simple means test, and full Government and hospital board subsidies are sought. An annual grant is received from the Wellington Cancer Society and the Williamson Trust. Generous donations are received from a variety of sources. Patients with private means or medical insurance may be asked for contributions, but no patient is denied admission because of economic circumstances. Assessment is flexible and liberal. The annual deficit which occurs is at present met by Calvary Hospital.

Demand
The following are the number of terminally ill patients admitted in 1978 and 1979:

<table>
<thead>
<tr>
<th></th>
<th>1978</th>
<th>1979</th>
</tr>
</thead>
<tbody>
<tr>
<td>Admissions</td>
<td>135</td>
<td>161</td>
</tr>
<tr>
<td>Deaths</td>
<td>69 = 51%</td>
<td>104 = 64%</td>
</tr>
<tr>
<td>Discharges</td>
<td>51 = 38%</td>
<td>69 = 43%</td>
</tr>
</tbody>
</table>

In the 12 months to 30 September 1980, a total of 230 patients had been admitted, with an average occupancy rate of 94 percent. In 1979, 43 percent of patients were discharged home, either to be nursed there, or to be readmitted at a later stage. The average length of stay was 24 days. In 1980, 48 percent of patients were under the age of 65.

There has been an improvement in the degree of pain control obtained over the last three years (Figure 1). In 1977, 12 percent of patients failed to achieve reasonable pain control, versus 4 percent in 1979. Pain is the most common and severe symptom to be managed, the frequency of other symptoms is as outlined in Figure 1. Emphasis on pain relief and support of the patient and relatives, has undoubtedly been more effectively performed within the hospice, which is not seen as an alternative to home care but rather extending and complementing the total care of cancer patients in the community.

Discussion
Hospices avoid the high technology approach to medicine of general hospitals, but emphasise a high staff to patient ratio to provide the nursing care, support, and symptom relief that these patients require. In September 1980, the Mary Potter Hospice cost $56.40 per bed per day, which is in line with the United Kingdom experience that hospice beds cost approximately 50 to 60 percent of the cost of a public hospital bed, while at the same time providing a higher standard of care in this particular field. So far, the development of hospices has mostly been outside the public hospital system. Hospices will undoubtedly develop in urban areas throughout New Zealand, and each one will be different in its form and funding depending on local resources, but all will have the action orientated programme known as the hospice movement. Such hospices will act as a resource centre with special skills and expertise in the care of the dying, and these concepts and skills will gradually become part of general medical practice, influencing the care of all patients.

Acknowledgments
The establishment of the Mary Potter Hospice has been possible because of the support of a large number of individuals and organisations. The Sisters of the Order of the Little Company of Mary, the Wellington Cancer Society, and its ladies’ auxiliary, Mr Roy McKenzie and the J. R. McKenzie Trust, Mr John Sutherland and the J. Sutherland Trust, the Wellington North Rotary Club, and numerous individuals from all walks of life. To these people we make grateful acknowledgment. Thanks to Mrs J. L. Harness for preparation of this manuscript.

Reprints. Requests for reprints to Dr A. J. Gray, Radiotherapist, Mary Potter Hospice, Florence Street, Wellington.

References
THE MARY POTTER HOSPICE

Since this paper was published the following statistics are provided for 1980:

The following are the number of terminally ill patients admitted in 1978, 1979, and 1980:

<table>
<thead>
<tr>
<th></th>
<th>1978</th>
<th>1979</th>
<th>1980</th>
</tr>
</thead>
<tbody>
<tr>
<td>Admissions</td>
<td>135</td>
<td>161</td>
<td>245</td>
</tr>
<tr>
<td>Deaths</td>
<td>69</td>
<td>104</td>
<td>130</td>
</tr>
<tr>
<td>Discharges</td>
<td>51</td>
<td>69</td>
<td>135</td>
</tr>
</tbody>
</table>

Deaths are recorded as a percentage of admissions, and discharges as a percentage of deaths.

In 1980, 69 of the 135 patients discharged were re-admitted (51% of the total).

*The discrepancy between admissions, total deaths and discharges, is due to end of year flow-over of patients.

The following statistics apply to 1980:

- Bed occupancy rate: 91.4%
- Average days stay overall: 29.74 days
- Long term beds (8): 153.68 days
- Short term beds (15): 20.21 days

Age range for admissions 1 April 1980 to 31 March 1981:

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 30 years</td>
<td>5</td>
</tr>
<tr>
<td>31 to 40 years</td>
<td>8</td>
</tr>
<tr>
<td>41 to 50 years</td>
<td>31</td>
</tr>
<tr>
<td>51 to 60 years</td>
<td>51</td>
</tr>
<tr>
<td>61 to 65 years</td>
<td>25</td>
</tr>
<tr>
<td>Total</td>
<td>120</td>
</tr>
<tr>
<td>66 to 75 years</td>
<td>87</td>
</tr>
<tr>
<td>Greater than 75 years</td>
<td>59</td>
</tr>
<tr>
<td>Total</td>
<td>146</td>
</tr>
</tbody>
</table>

Admitted from:

<table>
<thead>
<tr>
<th>Source</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home</td>
<td>178</td>
</tr>
<tr>
<td>Public hospital</td>
<td>52</td>
</tr>
<tr>
<td>Indirectly hospital</td>
<td>15</td>
</tr>
<tr>
<td>Number of cancer patients</td>
<td>244</td>
</tr>
<tr>
<td>Other illnesses</td>
<td>22</td>
</tr>
</tbody>
</table>
APPENDIX XIII

DESCRIPTION OF THE TE OMANGA HOSPICE

The philosophy of those working on this programme, which started in 1979, is of the home as the ideal environment for terminal care. Consequently, much of the programme of care, which includes a multi-disciplinary home care team, telephone advisory service, day care, and in-patient unit, palliative care clinic and bereavement service is community centred rather than institution centred. This is seen to have financial as well as humanitarian advantages. Emphasis is placed on the patient and family group as the unit of care, rather than the terminally ill patient in isolation. Education and research are seen as important elements in the Te Omanga programme.

The following table outlines the bed occupancy and average length of stay of patients admitted to Te Omanga Hospice between October 1979 to July 1981:

<table>
<thead>
<tr>
<th>In-patients</th>
<th>1979</th>
<th>1980</th>
<th>1981 (7 months)</th>
<th>1981 (Projected)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Admissions</td>
<td>22</td>
<td>173</td>
<td>120</td>
<td>206</td>
</tr>
<tr>
<td>Discharges</td>
<td>9</td>
<td>113</td>
<td>89</td>
<td>-</td>
</tr>
<tr>
<td>Deaths</td>
<td>7</td>
<td>60</td>
<td>36</td>
<td>-</td>
</tr>
<tr>
<td>Discharge Rate (%)</td>
<td>56</td>
<td>65</td>
<td>71</td>
<td>-</td>
</tr>
<tr>
<td>Bed Days</td>
<td>281</td>
<td>1440</td>
<td>823</td>
<td>1410</td>
</tr>
<tr>
<td>Average Patient Stay (days)</td>
<td>17.5</td>
<td>8.5</td>
<td>6.9</td>
<td>-</td>
</tr>
</tbody>
</table>

| Out-patients | |
|--------------|------|------|----------------|
| Patients cared for | 22   | 142  | 71             | 122              |

*The discrepancy between admissions, total deaths and discharges, is due to end of year flow-over of patients.

"THE TE OMANGA HOSPICE CONTINUING CARE PROGRAMME"

Function of the Hospice:

Despite the rash of hospice units which have appeared throughout the western world during the last 10 years, little has been written concerning the conception, gestation, birth and neonatal period of a hospice. The Te Omanga continuing care programme is the first such hospice programme in Australasia, and the aim of this paper is to describe the programme and its development and outline some of the major lessons which have been learnt and which may be useful to others planning similar programmes.
Philosophy of Hospice:

It is unfortunate that the term "hospice" has become synonymous with a building which houses dying patients. Hospice is, more accurately, a philosophy of care of the whole patient which emphasises the identification and solution of all patient related problems, be they physical, emotional, spiritual, financial, domestic or social.

It should be recognised that the family of the dying person also has problems, and is suffering, and the unit of care should thus be the patient/family group. Treating the dying individual in isolation results in a failure to identify and solve all his problems.

At Te Omanga, this philosophy is expressed in an integrated programme whose goals are:

1. To allow the patient to actively live until he dies. Patients are considered to be living, rather than dying, and their problems are therefore managed as aggressively as those of any other patient. If a patient has pain, tomorrow is not considered soon enough to control that pain. A glance at the number of patients in bed, rather than up and about, in any hospital ward will demonstrate that we live in a society which considers that a diagnostic label implies sickness and that sickness must result in the inability to lead a reasonably normal life. This assumption is patently invalid and all patients are encouraged to lead as active a life as possible.

2. To allow the patient to die comfortably, with dignity and within his own home if at all possible. Comfort is possible for virtually all patients; symptoms can be palliated if sufficient attention is paid to detail. It is accepted that death is not always dignified, but it is made less dignified by isolation from the family group and by high technology medicine with its tubes, machines and emphasis on the disease rather than the person. Home might be defined as the place where a person wishes to be; it is the place where most normal life activities occur and death is a normal life event.

The emphasis in both these goals is on the home, rather than the institution, as the preferred environment; the Te Omanga continuing care programme has thus discarded the practice of moving the patient to the caring agency or facility and replaced it with a policy of taking health care personnel and facilities to the patient. Such a policy has financial as well as humanitarian advantages.
Terminal care involves the skills of many health professionals and these care givers should be, philosophically, a team rather than a group of individuals. The members of the team include doctors, nurses, a physiotherapist, psychiatrist, occupational therapist, social worker, pharmacist, dietitian and clergy and such a team should be able to accept that, in many ways, the patient family group is the team leader.

History of the Te Omanga in-patient Unit

Te Omanga Hospice is a project which started with the experience of the Community Domiciliary Nursing Trust, a charitable trust whose interest include the provision of nurses to help with the care of dying people within their own homes. It was apparent from the experience of the trust that many such people received inadequate care. If admission to a more formal facility was necessary, the only such facility available was a hospital where the environment is far from suitable for the dying patient. On occasion patients remained at home because of the shortage of beds in acute hospital wards or because of the reluctance of hospital personnel, whose training is geared to curing, to fill a bed with a patient for whom there is no hope of cure. As a result of these perceived inadequacies a public meeting was called on 5 July 1978 which was attended by a large number of the general public in the Hutt Valley. At this meeting a steering committee was established whose task was to plan and finance a small in-patient unit for those dying with advanced cancer in the Hutt Valley. The result of their efforts is the Te Omanga Hospice which was officially opened by the Minister of Health in September 1979.

The Te Omanga Programme

The home care service is the spearhead of the programme and combines the expertise of hospice staff with the skills and knowledge of the family possessed by the general practitioner and the resources of the various statutory and voluntary agencies.

At the request of the general practitioner, the hospice director and oncology nurse are available to visit patients in their homes. Other members of the home care team are involved as necessary for the individual patient/family group. The team makes a detailed assessment of the clinical, nursing, social and emotional needs of the patient and family and suggests a programme of symptom control, nursing procedures, family support and involvement and any other measures that would improve the quality of the patient's life. Relief of pain and suffering may thus be achieved within the security of the patient's own home. The nurse or doctor then visit regularly to advise on appropriate regimes of care so that continuity of specialist supervision is maintained and maximum use is made of community and hospice resources. The regular visiting by this nurse reassures the patient and enables the family to play
its part in a new confidence based on her understanding of
their feelings and fears and her guidance on practical
problems. Other members of the team are available to visit
the patient at home should this be necessary. The patient
remains at all times under the overall care of the general
practitioner whilst at home, unless the latter specifically
requests the hospice team to take over patient care, and is
allowed to live and die with dignity and in peace.

The patient retains his dignity because he is dying in fami-
liar surroundings, assisted by his loved ones but still
partly in control of his own affairs and destiny. He is not
subjected to the hospital discipline which is often designed
to fulfil the wishes of health professionals, rather than
those of the patient. He can set his own pace and limits
and is helped to remain active and useful for as long as
possible. The home care team are his guests rather than
begrudging hosts who feel that he is blocking a bed. The
patient dies in peace because the home care team will not
allow him to suffer pain and because they have time to spend
with the patient, to listen to his fears and dispel his
doubts.

A 24 hour telephone advisory service provides support for
families at home. Patients and their relatives are
encouraged to ring at any time of the day or night about any
problem. Often such problems are trivial, but may achieve
enormous proportions during the night when all is silent and
it seems a long time until dawn. The telephone is manned by
experienced nurses who know about the family and its
problems and are able to offer advice and reassurance or
activate medical or nursing help where appropriate.
Curiously, this service has never been abused.

This facility is also available to advise medical prac-
titioners anywhere in New Zealand on terminal care or symp-
tom control problems.

Te Omanga in-patient facility is a private house, in an
ordinary residential street, which has been converted to a
seven bed terminal care unit. Considerable care has been
taken to preserve a homely atmosphere and yet facilities are
available for all medical and nursing procedures other than
major surgical interventions.

Patients are only admitted if it becomes impossible to
manage them satisfactorily at home. Although the reasons
for admission are many, the commonest is when control of a
symptom complex requires more intensive supervision than is
possible within the home. Patients are also frequently
admitted in order to rest the caring relatives. If this
need is identified early, relatives recover rapidly and are
happy to take the dying individual home again. If this need
is not met in time, the recovery period is prolonged and
relatives may feel unable ever to take the patient home.
Because patient problems are managed aggressively the
average stay is only 10 days and more than two-thirds of all
admissions are discharged home.
Day care of patients offers several benefits:

1. The caring relatives, who on the whole cope extraordinarily well, find it difficult to leave the patient alone even when, as is usual, constant supervision is unnecessary. The provision of day care within the inpatient unit gives the relatives official free time.

2. Patients are able to meet each other and discuss—in an informal manner—their problems and worries with others with similar problems. Frequently, these contacts develop into supportive friendships which continue through telephone calls or visits at home.

3. Patients, who may later need admission, are given the opportunity to become familiar with the unit and the staff who work there.

The palliative care clinic is a consultative clinic for patients, who, for a variety of reasons, it is inappropriate to visit at home.

The bereavement group. It has been emphasised that the unit of care is the patient/family group and care does not, therefore, cease with the death of the patient. Grief is, in the majority of cases, a perfectly normal process and the members of the bereavement group are not trained health professionals but are chosen because they are particularly human beings who bring with them their own life experiences and humanity. An appropriate group member is introduced to the patient/family group before the death occurs and continues to be in contact for a minimum of two years. Grief does not cease after a month or two and it is felt that prolonged follow-up is necessary and this contact most naturally occurs within the home where the grieving relatives are most at ease.

The patient care programme outlined above is but one function of the hospice. The Te Omanga Hospice has two other important roles.

Education. Until very recently, terminal care had no part in most undergraduate curricula. Whilst it is accepted as impossible and even undesirable that medical students should cover all areas during their undergraduate years, it is important that basic concepts and principles of management are acquired during this period. Fifth and sixth year medical students spend time at Te Omanga and thus become familiar with the concept of total patient/family group care.

Nurses from throughout New Zealand spend time attached to the inpatient unit and a repeating terminal care nursing course is shortly to commence which will run in conjunction with such attachments. All nurses, be they medical, surgical, district or practice nurses, are involved with dying patients and their families and all can benefit from this type of inservice training. In addition, social workers, physiotherapists, occupational therapists and general practice registrars spend periods at Te Omanga.
The attitudes of the lay public, as well as those of health professionals, to death and cancer are often founded on misconceptions and an extensive programme of talks to service clubs, church groups and societies of various types is under way. It is hoped that in this way, as well as through individual contact, attitudes will slowly change.

Research. Terminal care is an area of medicine which, like any other area, will only advance through research. Currently much of the management of the dying patient is empirical and there is a need to evaluate and rationalise existing management methods as well as develop and introduce new methods. Research, therefore, forms an important part of the Te Omanga programme.

Funding. The costs of such a programme are largely the costs of the in-patient unit. The capital and running costs of the Te Omanga in-patient unit come from individuals, service clubs and organisations within the community such as the J.R. McKenzie Trust and the Cancer Society. The Government Bed Subsidy, payable for all occupied private beds, is claimed. It is emphasised that the service is free to patients. Salaries make up some 80% of the running costs and the employment of volunteer staff for all but nursing duties maintains costs at the lowest possible level as well as allowing significant active community involvement in this community project.

Discussion

Several important decisions were made during the planning and initial running period some of which may be useful to others planning similar projects:

1. The project arose from the identification of a problem within the community. Members of the community then deliberately set about solving that problem without recourse to Government. It was felt that the bureaucracy and consequent lack of flexibility which extensive government involvement would entail was inappropriate to such a project. Furthermore, the over all financial cost to the community of an efficient, privately funded facility is likely to be less.

2. A deliberate decision was made to purchase and alter an existing property, rather than build a purpose built hospice unit. This decision had financial advantages as well as allowing the purchase of an existing centrally situated building within the community, including the atmosphere possessed by such an older property which is so important for optimal terminal care.

3. The provision of seven in-patient beds is sufficient for the population of 175,000 in the Hutt Valley drainage area, provided that the outreach services operate effectively and that patients' problems are managed aggressively. This figure is based on over-
seas statistics but has been remarkably accurate—during the first year, no patient has had to wait for admission and bed occupancy has been 75%.

4. The programme should be staffed by salaried and volunteer personnel. Payment of nursing staff allows for a full time commitment and thus continuity of care whilst the use of volunteers for all other professional and lay posts permits continued, very active, community involvement in a community based project.

5. The screening of staff of all types who wish to be involved in such a project must be rigorous. Individuals differ and a nurse, for example, who is excellent on a hospital ward is not necessarily able to deliver optimum patient care in this specialised field. Staff of all types are at risk in such an environment and considerable care is taken to exclude people who might be harmed by such an exposure and guide them in an alternative direction. All staff are employed initially for a three month period which results in a review being undertaken by both staff member and hospice authority at a particular time. If either person feels that hospice work is inappropriate for the individual, a comparatively non traumatic parting of the ways can occur. No screening method is perfect; one of 12 nurses and one of 70 volunteers has left because of unsuitability.

6. The service provided by such a programme should be free to patient; dying people and their families have enough problems without worrying about medical or hospital bills.

7. A staff support system is important for those who work in this potentially traumatic area and should be available in a semi formal and informal manner. Team meetings are held weekly with an open agenda and the team psychiatrist, medical director and nursing director operate an open door availability. A large, pleasant out-door area with an adjacent house is shortly to be made available to staff who either wish to be alone or with one or two others. This facility will be provided away from the in-patient unit.
8. No attempt has been made to translate a hospice programme from another country to New Zealand. There is evidence that the behaviour of tumours of the same histological type differs from country to country, and it is also known that the problems caused by these tumours vary with each country. The statutory and voluntary agencies available within this country have strengths and weaknesses which differ from those elsewhere in the world. A deliberate attempt has therefore been made to identify the problems and to solve them by integrating the Te Omanga Programme with the various statutory and voluntary agencies.


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