

PALLIATION PLUS PROGRAM.

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20th October 1984.

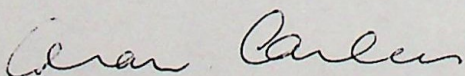
Mr. Graeme Shearer,  
Trades Hall,  
BALLARAT..3350

Dear Graeme,

You are invited to the first meeting of the steering committee, as detailed below. Please extend this invitation to any others you know of who are interested in improving the care of the dying in Ballarat and surrounding districts, and feel free to write direct to me with your views if you are unable to attend this meeting.

The meeting will be informal and there will be no voting, elections or passing of resolutions. I hope that from the meeting will emerge smaller groups working towards particular ends - the generation of specific proposals to be put before a future public meeting. I have designated what I see as some of the tasks of those groups, which are not numbered in order of priority, nor necessarily complete in their scope. I have chosen a working title for our group which does not prejudge the final nature of the program I trust will eventuate except in one important respect - it will not be a program supporting only the needs of dying patients. As I trust you are all aware, the needs of caring relatives, friends and professionals involved in the care of the dying are not always well met in our society, and our program will be looking to improve their support.

I look forward to meeting with you.



Meeting Thursday 1st November at 7.30 p.m.  
Ballarat Base Hospital Function Room 2.



## PALLIATION PLUS PROGRAM

### Historical Background.

Whereas the active treatment of diseases such as tuberculosis and cancer is a relatively recent concept, the palliation of the slow dying and prolonged suffering so characteristic of such diseases predates history. While family support has always been crucial to optimal care, organised supplementation of family support has been recognised as needed for many centuries. The Crusaders established houses of hospitality for pilgrims to the Holy Land and hospitals to nurse those afflicted by illness far from home. The Hotel Dieu was established in France in 1443 to nurse the ailing poor; the rich of the time were able to afford care in their own homes. In 1879 Mother Mary Aitkenhead founded the Irish Sisters of Charity and Our Lady's Hospice in Dublin, devoted to the care of the dying and the first of many hospices to be so called. Mary Aitkenhead recognised in her choice of name the clear continuity between her work and the hospitality of the Crusaders and others.

In 1952 the Marie Curie Memorial Foundation and the Queen's Institute of District Nursing in the U.K. researched the needs of those dying at home and opened their first hospice - Tidcome Hall Home in Devon. In 1958 the Day and Night Nursing Service was introduced in the U.K. to give relief, assistance and valuable sleep to those caring for the dying at home. There has since been worldwide spread of what is commonly referred to as the hospice movement, with cancer displacing tuberculosis as the main illness among patients cared for by the many organisations which have come into existence.

The interest of the Ballarat Trades and Labor Council in this subject follows a long tradition dating from the Mediaeval Guilds whose members, in the 13th Century, were expected to spend some of their nights nursing and tending the needs of their sick and injured workmates. The Ballarat Base Hospital was established by goldfields workers to care for their injured and sick colleagues, as were many similar institutions.

Recent developments in terminal care have shown convincingly that relief of pain and suffering is an achievable goal in virtually every dying patient. Through better understanding of the use of medication to relieve pain when prolongation of life is not being primarily sought and through better understanding of the complexities of suffering the needs of the dying can now be met in a realistic way, without need for dismissal by statements that nothing more can be done for them. The removal of fear - of a painful death which distresses loved ones - can now be achieved and in consequence it is often found that when such fear is removed then with it goes the wish for a quick death or a death in hospital. Providing facilities for the care of the dying at home is not cheap, but it proves less costly to the community in both economic and moral terms than providing those facilities in a hospital.

There are now strong, well organised groups supporting the care of the dying in several Australian communities, notably Perth, Melbourne and Geelong. Not all have organised hospices as such, but all have recognised the need for a responsive, round the clock nursing service for those dying at home. Such a service will be an essential core to our program. Other elements, recognisable in all modern "hospice" groups, are the provision of expert advice on palliative care, non-medical support from religious and social workers, support for relatives which extends beyond the funeral stage and a large sense of community involvement.



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### Task Groups and Discussion Notes.

#### Task Group 1. Organisation.

The program needs an organisational structure and a constitution. It is expected that similarly oriented organisations will be worth studying. Dr Taffy Jones, from Geelong, has suggested that early planning to achieve tax exempt status is highly desirable.

#### Task Group 2. Finance.

This group should explore possible sources of financial support from within the community and from Government. While assured of some help from both categories by the experience of other organisations, the quantification of requests and likely responses will need to be done soon and with sufficient accuracy to allow expenditure planning. It is proposed that as a basis of financial planning it should be assumed that all services under this program will be free of net cost to the patients and their relatives. The experience of other groups is that such a policy is more than justified by the generous donations and bequests which follow from considerate and cost-free care.

#### Task Group 3. Home Care.

This group will establish admission criteria and protocols for assessment, nursing and medical care in the home. It is proposed that each patient be admitted to the program on referral from a general practitioner who will remain in overall control of care. Proposed admission criteria are (a) patient expected to die within weeks or months; (b) patient not currently being investigated or medically treated in the hope of cure or prolongation of life (although seeking of non-medical cure would not warrant exclusion). It is not proposed that only cancer sufferers be admitted. Provided that the program could discharge those manifestly not dying there is no pressing need to exclude non-cancer patients thought to be terminally ill. Home nursing should be available when needed at any hour and there should be available the option of first calling in a nurse to handle an acute problem ahead of a doctor. In the context of terminal care, doctors may delegate and nurses accept certain responsibilities to facilitate the relief of suffering and those responsibilities need definition. It is estimated that in any one year in Ballarat the program would arrange about 1800 home nursing visits spread over about 50 individual cases. At any given time there would be between 3 and 10 patients on the program being cared for away from home.

#### Task Group 4. Away From Home Care.

From the above estimates, the establishment of a separately housed unit to care for those who for one reason or another, for short or long periods, cannot be cared for at home would seem impractical. Rather it is proposed that existing hospitals and nursing homes undertake to provide that care. The special needs of the dying suggest that such care have some or all of the following features:

- (a) Admission to be at the request of patients or caring relatives at any hour,
- (b) Admission decisions to be delegated to designated nursing personell with the responsible doctors to be informed as soon as practical,
- (c) Continuity of care, by doctors, nurses and caring relatives etc. to be undisrupted by transfer from home.
- (d) Properly kept orders for and records of treatment at home to be



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Task Groups and Discussion Notes (cont.)

acceptable by institutional staff as the basis for continuing care. Task Group 4 will analyse this proposal and respond with appropriate suggestions for this aspect of the program.

Task Group 5. Liason and Publicity.

This group will propose ways of informing the public and involved professionals of the progress of the program. Reluctantly it is suggested that yet another news bulletin be periodically produced for distribution but it should be born in mind that doctors in particular already have crowded mail boxes.

Task Group 6. Documentation and Research.

It is proposed that each case handled by the program be documented by (a) personal records (b) medication records (c) medical notes and (d) nursing notes of a standard compatible with hospital requirements on the one hand and the time constraints of the caring professionals on the other. This group should consider the standards of documentaion required and make detailed proposals. It should also consider methods of documentation such as transcription of dictated notes which might prove more practical than reliance on written notes. It is proposed that ownership of all notes generated within the program reside with the program, provided that institutions involved in the care of particular patients be able to retain copies of relevant notes. It is proposed that the program should have a policy on the use of documents for legitimate research. This group will assess these proposals and related matters.

Task Group 7. Labour Organisation and Training.

This group will formulate proposals on the allocation of tasks within the program, standards of training and assessment for particular tasks and avoidance of disputes. Programs similar to that we propose have used volunteers for certain tasks, because they save money, because they keenly offer their services which offers would be callous to refuse and because they add elements to the program which cannot otherwise be obtained. Problems associated with the use of volunteers include trade union opposition to working with them, excessive enthusiasm which leads to inappropriate allocation of tasks and irregularity of committment. All these and other like problems need to be anticipated. The special needs of the dying are not necessarily well understood even by qualified professionals and a training program designed to teach and test for the necessary skills must be established. It might include the following:

- (a) The dying process.
- (b) Communicating with dying patients.
- (c) Mourning and Grief.
- (d) Philosophies of terminal care.
- (e) Crisis management.
- (f) Pain reduction.
- (g) Coping with personal stress.

Task Group 8. Pastoral Care.

The dying process often brings to the surface religious and personal needs which, if unmet, constitute a source of suffering. The anticipation of such needs is an important aspect of palliative care. This group should identify the best means of providing that care and of maintaining the necessary liason between professionals required to do so.