

STEERING COMMITTEE MEETING 29th November 1984

At a well-attended meeting the following reports from task groups were presented:

Management, Finance & Publicity Dr. Ed Davis.

It has been decided to incorporate our organisation under the Associations Incorporation Act 1981 which step will, at minimal cost, protect the future administrators by limiting their liability. For this purpose a set of rules has been drafted by our legal advisor Penny Wright. Copies are available for all wishing to study them. A public meeting has been called (see below) to adopt those rules and it is expected that our organisation will then become incorporated and registered under the Hospitals and Charities Act as a charitable organisation with tax exempt status.

Bob Fewster is obtaining a P.O. Box number and registering us for reduced rate mailing. Allan Bath and Barry Bolger are arranging for interim finance for our ongoing activities from a variety of sources and John Garner is arranging publicity, to be focussed initially on our first public meeting. The Anti-Cancer Council of Victoria has been informed of our existence.

The proposed management structure is a Committee of Management elected by all members of the organisation at its annual meeting with office bearers elected by the C.O.M. from within its ranks. Many if not all members of the present Steering Committee are likely to find themselves serving on subcommittees which the C.O.M. will ask to oversee aspects of the program. The C.O.M. will employ staff and appoint the Medical Director and Nursing Administrator. (The alternative arrangement, whereby the annual meeting elected office bearers, was discussed and rejected at this Steering Committee Meeting).

Edna Bolger has kindly accepted our invitation to act as interim secretary. It is anticipated that accomodation will be found in B.B.H. for her activities, thus relieving Ed's secretary of her additional workload. In bearing that load she has earned our gratitude.

Home Care Sr Gwenda Sharp.

All Ballarat nursing teams are now actively involved in the task of planning nursing care for the dying and in particular Margaret Seelenmeyer of Abel Home Nursing has welcomed our invitation to become involved since the first Steering Committee meeting. Much valuable insight into the task ahead has been obtained from discussion with other hospice nursing teams. In Frankston, 24 hour domicilliary nursing care is achieved by contracting district nurses. Peter McCallum Clinic patients in Melbourne who require multiple visits daily and/or after hours visits may have their care shared between the Royal District Nursing Service, the Peter McCallum Hospital Visiting Nurse Service and a Hospice Care Program. Guidelines for shared patient care have been received by us. We have also received information sheets from Citimission Hospice Program outlining their philosophies of care. The Mercy program initially involved having nurses on call at night but this produced excessive fatigue in nurses and has been replaced by night staff. Visits are planned in the near future to examine first hand the work of Geelong Hospice and the Mercy team .



Home Care (cont.)

All teams so far contacted have stressed the importance of adequate training and staff support as a means of avoiding a high drop-out rate. Some services have in that way achieved the goal of low staff turnover. There is also an observable direct relationship between the proportion of patients dying at home and the number of necessary night visits and it is likely that if our program aims to facilitate dying at home it will need to roster nurses on duty for three shifts per day.

The R.A.N.F. advises that it will not be possible to have nurses seconded to the program, but it may be possible for the program to contract with existing domicilliary nursing services for the provision of nurses and necessary emergency and holiday replacements. The alternative is for the program to create new nursing positions. There are reservations about the concept of using the same nursing team for at home and away from home care but if separate teams were used, each would visit the patients on occasions when they were under the care of the alternate team. (It is not yet clear whether such visiting would be in the nature of voluntary work or constitute part of nursing care, but the latter is clearly the more appropriate concept if funds and staffing permit.)

Those interested in details of the work of this task group should contact Gwenda Sharp or attend the next meeting: 4 p.m. Tuesday 18th Dec. at Ballarat & District Nursing Society.

Away From Home Care Dr John Stickland.

The Group made the following recommendations:

1. Ballarat Hospice Care should lease two beds in designated wards from St John of God Hospital, Ballarat Base Hospital and Queen Elizabeth Geriatric Centre. The cost to the program would presumably relate to utilisation but would reasonably include a holding charge.
2. The problems of allowing district nurses to care for patients within the institutions are thought to be insurmountable and it is advised that senior nurses on the wards where Hospice beds are leased be trained in hospice care and that part of such a nurse's work be visiting at home those patients on the program who have indicated a likely preference for away from home care at the nurse's institution.
3. Admission should be through the program and not normal admission procedure. Whether doctors or nurses sanction admission will be decided in the light of experience.
4. The Director of Ballarat Hospice Care should be on the consultant staff of Queen Elizabeth Geriatric Centre and Ballarat Base Hospital and all doctors who wish to care for their own (public) patients within the program should be his associates. (Note that while all current G.P.s are accredited for private practice and could register as associates to a unit at the Base Hospital, relatively few have any practice rights at Queen Elizabeth Geriatric Centre.) Resident Medical Officer care of patients should correspond to the care they would give if the patients were not on the program. It seems unlikely that sessional payments from hospital funds will be offered to the Director or any of his associates.
5. Relatives should have access to patients at all times during away from home care and be encouraged to assist with that care. Accomodation will be provided if possible for out of town relatives.



Training Dr Adri van der Knijff

The group was unanimous in its opinion that adequate training will be essential for success of the program. Training implies selection of staff for suitability, initial training, periodic assessment and ongoing training and support. Programs which are established and have relevant training facilities should be utilised as much as possible for both training and assessment; this is being further investigated. A general seminar to provide information for those considering working on the program should be held as soon as possible.

Medical Training should be by seminars on pain control, palliative procedures, total symptom control and counselling, and the attendance of all doctors wishing to control the care of patients on the program should be encouraged. The group is very concerned that having a multiplicity of doctors caring for patients will create a multiplicity of variations in treatment and poor team spirit. A consultant expert in palliative care could be enlisted to advise both doctors and nurses on the finer points of terminal care and, if working part-time, such a consultant need not necessarily be locally based. (In discussion it was noted that existing nursing teams are used to working with about 50 G.P.s and about as many specialists. It has been assumed so far that the Medical Director of the program would be available and competent to act as consultant to less experienced doctors.)

Nursing Training should consist of specific classroom teaching and on-the-job training in Hospice work.

Volunteers actually working in a patient support role would also need specific training. Because a unified, team approach is so important, attendance by all those working on the program at training sessions held locally should be strongly encouraged. (This applies to doctors, nurses, pastoral care and social workers. It was pointed out in discussion that following any of those professions was no sure indication of competence in handling dying, death and grief. There is reason to believe that competence can be acquired by most with training and maintained by adequate support, but the program needs to be robust enough to reject those who fail to show competence for whatever reason.)

Labour Organisation Graeme Shearer

Geelong Hospice employs 1 nurse full time and 6 nurses part time. An office worker is paid for  $2\frac{1}{2}$  days a week and a doctor is paid for 1 day a week. Nurses are paid under District Nursing award rates. (currently \$342.70 per 38hr week for 1st years, \$9.01 per hr. part time plus 25% casual loading where applicable. There is a 50% loading for work done between Friday midnight and Sunday midnight. )

The example of Geelong should be followed in that all nursing by qualified nurses was paid for from the outset and skilled office work became salaried as soon as finances permitted. There seems no problem with the use of volunteers in a supportive role.

Discussion was held with Shirley Carson of R.A.N.F. about nurses making what would be medical decisions were the patient not dying (such as decisions to admit patients to hospital Hospice beds) and it was felt that provided there was good quality continual consultation between doctors and nurses such delegation of responsibility should not cause problems.



Documentation Robert Broughton.

Separation To comply with registration requirements it will be necessary for hospitals to retain records of all patients on the program who are admitted. However, the basic documentation should be a skeleton history and other notes, rich in information, which would remain with the patient until death or discharge and be the property of Ballarat Hospice Care. (In discussion it was suggested that speculation which could be detrimental to patient morale might best be recorded in private notes, but that in general terminally ill patients benefit from access to honest case notes.)

Format. The minimum set of documents would consist of a master problem sheet, a domicilliary care record, pathology sheets, progress notes (which could contain contributions from medical, nursing and paramedical staff and family members) referral and initial assessment forms. In all cases existing stationery should be used as the cost of printing new documents for this program would not be justifiable. The best available referral for assessment form would be that used for Q.E.G.C. referrals. There should be no insurmountable problems in the use of the domicilliary care record (which would contain clear and current orders for treatment) as the basis for initial treatment on admission to hospital. All progress notes should be written in at the time of seeing the patient and annotated to allow clear understanding of who made which notes.

Research. It is not thought likely that there will be a great demand for access to individual records. Utilisation statistics should be kept which will allow the following information to be extracted: No. patients by age, sex and disease type, average duration of treatment at home and in hospital, average length of individual periods of hospitalisation, average cost of treatment to the program, average number of day & night home visits (and ratio), percentage dying at home.

Pastoral & Social Care Sr Eugenia Brennan

Definitions: Pastoral Services endeavour to facilitate the person's the family's and the community's working out (often in the context of religion) the spiritual significance of the present situation and the human response to it. Social Services endeavour to facilitate the person's the family's and the community's working out of relationships with self, family, community and society by making the most appropriate and effective use of personal and community resources to attain those goals which the client or client group perceives as desirable.

Needs The Dying need to question their past, present and future and consider relationships with themselves, others and God. Families of the Dying have those needs and also need to make decisions and deal with the practicalities of life without the dying. Care Givers have to cope with a heavy emotional load and must reflect on their work and the feelings it engenders to obtain healthy resolution of those feelings and satisfaction in care giving. For this work they need adequate training.

Relationships The relationship of pastoral and social care givers with other care givers must be that of team members. Their contribution should be recognised and honoured in protocols and records.

Care-Givers. All those involved in the care of the dying have some potential contribution to make to this aspect of the program and each must recognise the gift of the others.



Pastoral & Social Care (cont.)

Referrals. Pastoral and Social Care may be required at any time from the point of entry to the program to the resolution of grief. The program must devise a mechanism for alerting P & S C personnel to the entry of a new person to the program. P & S C workers need training in the art of offering service when appropriate.

Choice of Name

The working title (Palliation Plus Program ) was replaced by unanimous agreement by Ballarat Hospice Care. (At a later stage the word "Incorporated" will be added to the formal title.) It was felt by the committee that the term palliation had little currency outside the medical profession but that hospice care was now a clearly understood concept.

Initial Goals.

Ballarat Hospice Care will be able to accept referrals in a few months time; the immediate obstacles are lack of organisation, lack of corporate status and lack of finance. If the first two are largely overcome but finances do not permit us to offer a full 24 hour care service it is likely that we can still function in the following way. Referred patients will be assessed for needs and any which can be filled by existing services will be met. All necessary aids to home nursing will be supplied on a loan basis with periodic upgrading if conditions worsen. (To this end the program may utilise volunteers to assist in assessment, delivery of aids and retrieval of aids due for return. It is anticipated that aids for loan currently owned by the Ballarat Base Hospital, Ballarat District Nursing Society, Red Cross and Queen Elizabeth Geriatric Centre would form the stock. Rather than finance the purchase of more stock, the Hospice program might facilitate the central computerised registration of existing stock and facilitate its utilisation. This concept is currently being explored by local occupational therapists.)

Relatives of patients could be offered day and night relief by volunteers who could minister to simple needs while those so relieved went out of the home to shop, relax etc. or went to bed for undisturbed sleep. Neither proposal requires substantial ongoing funding but both demand a robust organisation and a pool of selected and trained volunteers.

The committee accepted these initial goals and it was noted that an early start in this form would be a significant achievement and a boost for morale and publicity.

The meeting closed at 9.45 p.m. and a few of us remained for coffee and to watch a documentary on St Joseph's Hospice.

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PUBLIC MEETING

Thursday 13th December at 7.30 p.m.  
Function Room 2, Ballarat Base Hospital.

Agenda: Adoption of a set of Rules to be the  
Rules of Ballarat Hospice Care Incorporated.

Only matters closely related to the above will  
be debated and voted upon.

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NEXT STEERING COMMITTEE MEETING Thursday 31st Jan 1985 at 7.30 p.m.  
Function Room 2 Ballarat Base Hospital.