

Principles for the  
Provision of  
Bereavement Support  
by Palliative Care  
Services in Australia

November 1998

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## 1 Executive Summary

This report is the result of a national study commissioned by the Commonwealth Department of Health and Family Services (DHFS) to develop and recommend a set of guidelines for the provision of bereavement support by palliative care services in Australia. As part of this study, Palliative Care Australia (PCA) has also developed a comprehensive bibliography, *Bereavement, Grief and Bereavement Support: A Bibliography*. Supplement to: *Principles for the Provision of Bereavement Support by Palliative Care Services in Australia*, available as a separate document.

While it is almost universally accepted that bereavement support is an integral part of palliative care, studies in Australia, America and Britain have shown that there are significant differences in how palliative care services identify what constitutes a bereavement support service. Further, while the process of grieving and its outcomes for the bereaved are well described in the literature, as are many interventions and programs for the bereaved, there are few studies which examine the provision of bereavement support by palliative care services or evaluate how component activities combine to provide an effective program.

Therefore, this study sought to develop a consensus among palliative care service providers around Australia on a set of principles for bereavement support programs appropriate for palliative care services in Australia. The study took the form of two questionnaires distributed to all palliative care service providers known to PCA as well as to a number of related organisations with expertise in the provision of bereavement support. The first questionnaire was sent to 308 organisations and was completed by 159, giving a response rate of 52%. The second questionnaire was sent to 285 organisations and was completed by 189, giving a response rate of 68.7%.

The first questionnaire was based on literature describing bereavement support provided by palliative care services and on Australian service providers' responses to the previous census conducted by PCA. Respondents rated the importance of specified components of bereavement support programs which included services and activities offered to the bereaved, assessment of and action taken for people identified as having complicated or crisis grief reactions, the provision of information, data collection, and support provided for staff and volunteers. Respondents also gave detailed recommendations concerning appropriate schedules for telephoning and visiting bereaved families, levels of education adequate for staff and volunteers providing bereavement support and counselling, the duration of support for the majority of families and desirable outcomes for bereavement support programs.

Thirty-one principles were derived from items selected from the first questionnaire. Included were program components rated as essential or very important by more than 75% of respondents as well as the most common recommendations. The second questionnaire asked respondents to indicate whether or not each of these principles should be included in or omitted from a set of principles for bereavement support programs appropriate for palliative care services in Australia. Also included was a section on risk assessment that had emerged as an important component of bereavement support.

The following principles were selected from the set presented in the second questionnaire using the criterion that more than 85% of respondents indicated that the principle should be included.

### **Principles for Bereavement Support Programs Appropriate for Palliative Care Services in Australia**

#### **Core Value**

- The provision of hospice and palliative care services includes grief and bereavement support for the family and other carers during the life of the patient and continuing after death.

#### **Aims**

- Services aim to support the bereaved as they adjust to life without the deceased.
- Services aim to assist the bereaved through the normal process of grief.
- Services aim to reduce the risk of physical and mental complications associated with grief.

#### **Structure**

- Bereavement support services are offered to the families and carers of all palliative care patients.
- Services are provided by staff and volunteers who have received specific education in bereavement support, grief and loss.

#### **Processes**

- Services will ensure volunteers and staff involved in bereavement support receive ongoing education and training.
- Services will provide supervision and support activities for volunteers and staff involved in bereavement support.
- Services will ensure that people with, or at risk of, complicated grief reactions are offered bereavement counselling or referred to specialist bereavement counsellors for follow-up.
- Services will use a risk assessment tool to identify people with, or at risk of, complicated grief reactions.
- Services will begin assessing families and carers for risk as soon as possible after first contact is made with the patient.
- Services will ensure that the bereaved are informed about services available to them including notices regarding events such as memorial services and group meetings.
- Services will provide education about loss and grief to the community.
- Services will collect data to evaluate outcomes.
- Services will collect data for planning/budget purposes.

### **Recommendations**

PCA recommends that:

1. the principles for the provision of bereavement support as part of a palliative care service, as set out in 7.1, form the basis of such programs as a minimum standard where bereavement support is funded;
2. the principles are used as a basis for evaluating current service provision through the national census conducted by PCA;
3. the principles form the basis on which standards for bereavement support are developed and form part of the accreditation process of palliative care services;
4. performance indicators be developed to monitor selected processes of bereavement support programs;
5. a research project to determine appropriate outcome measures be conducted; and
6. outcomes be correlated with the structure and processes in order to test the findings of this study.

## 2 Background

In 1996 the Commonwealth Department of Health and Family Services (DH&FS), on behalf of the Australian Health Ministers' Conference, undertook a review of the Commonwealth funded Palliative Care Program (PCP). The first stage of this review examined outcomes and effectiveness of the PCP and looked at the appropriateness of current palliative care services in Australia, at the same time seeking to identify gaps in current palliative care servicing arrangements.

These issues were examined by Dr Draginja Kasap.<sup>1</sup> Kasap's investigation into bereavement services led her to conclude that, while bereavement support is accepted as a feature of palliative care service provision, its provision "is somewhat inconsistent both within States and Territories and generally across the country".<sup>2</sup> The level and type of bereavement support activities were found to be extremely varied, with bereavement support being offered for the most part as follow-up contact with family and carers, and referral to appropriate professionals for expert advice.

In the light of these findings, Kasap suggested that the then Australian Association for Hospice and Palliative Care could be approached "to facilitate a national study into current philosophies and practices so as to develop some overall consensus and provide a basis for planning and ongoing provision of services".<sup>3</sup> Her recommendation to the Commonwealth was that "the current provision of bereavement services be further assessed in order to identify the basis for providing support to carers and families, and meeting the specific service needs of those family members who require professional counselling" (Recommendation 4).<sup>4</sup>

The Commonwealth supported the recommendation and undertook to "explore and develop, through the current PCP activities, a set of principles for appropriate bereavement support".<sup>5</sup> This support was further evidenced in the Commonwealth's National Strategy for Palliative Care in Australia.<sup>6</sup> One of the strategies for the maintenance and improvement of the quality of palliative care services is that "national principles are developed for provision of appropriate bereavement support". This is part of the Commonwealth's commitment to developing a coordinated approach to providing bereavement services.<sup>7</sup>

In 1998, DH&FS commissioned PCA to undertake a national study and recommend a set of guidelines for the provision of bereavement support by palliative care services in Australia. This report is the result of that study.

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1 Kasap and Associates, *Report to the Palliative Care Program Review Stage One: A Report by Kasap and Associates Pty Ltd to the Palliative Care Program Review Steering Committee*, 1996

2 *ibid*, Executive Summary, page xix

3 *ibid*, Executive Summary, page xix

4 *ibid*, page 55

5 in Commonwealth Department of Health and Family Services, *Commonwealth Response to Recommendations contained in the Stage 1 Report to the "Palliative Care Program Review 1996"*, 1997

6 Commonwealth Department of Health and Family Services, *Palliative Care: A National Strategy for Palliative Care in Australia 1998-2003*, 1998

7 Commonwealth Department of Health and Family Services, *Palliative Care: Background for A National Strategy for Palliative Care in Australia*, 1998, page 7

### 3 Introduction

It is almost universally accepted that bereavement support is an integral part of palliative care. The World Health Organisation, in its 1989 definition, states that palliative care "offers a support system to help the family cope during the patient's illness and in their own bereavement". Similarly, the Australian Association for Hospice and Palliative Care's 1994 definition states that "the provision of hospice and palliative care services includes grief and bereavement support for the family and other carers during the life of the patient, and continuing after death". These principles, however, are not universally applied.

A national survey of palliative care services in Britain<sup>8</sup> found that 84% of respondents provided some type of bereavement follow-up although a further 17% expressed their intention to develop such services. Of the respondents who already provided bereavement follow-up, 16% identified onward referrals to other agencies as the strategy used, and only 53% identified activities such as telephone contacts, personal visits or group sessions and social meetings as their bereavement strategy. Almost a third (31%) did not respond or did not know the answer to the question on the type of bereavement support provided.

Lattanzi-Licht,<sup>9</sup> reporting on a national study conducted in the United States, did not give the proportion of hospices offering bereavement support, concluding that the results of her survey of United States hospices were complicated by "the fact that all hospices consider that they offer bereavement services, whether formal programs or casual efforts". Variations in the programs provided were similar to those found in Britain. The most frequently offered services were phone calls, visits, letters or notices, literature and materials on grief, group meetings and memorial services, although services varied in the priority they afforded these activities. The study estimated that approximately 80% of bereaved families were offered bereavement support.

It was clear from both these studies that there were significant differences in how services identified what constitutes a bereavement support service. The position in Australia is similar.

The National Census of Palliative Care Services<sup>10</sup> found that 81 services (47.9% of respondents to the census) reported provision of a bereavement program. When asked to report on the bereavement activities carried out, however, 113 services (66%) were able to describe the schedules they used to telephone bereaved families, 133 (77.7%) indicated procedures to visit the bereaved and 116 services (67.8%) indicated that bereaved families were offered a memorial or friendship service. The census also found that many more than the 81 services who said they provided bereavement support indicated that they have staff involved in bereavement support.

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8 Payne, S A and M Relf, "The assessment of need for bereavement follow-up in palliative and hospice care" in *Palliative Medicine*, 1994 Vol.8, pp.291-297

9 Lattanzi-Licht, Marcia E, "Bereavement services: practice and problems" in *Hospice Journal*, 1989 Vol.5(1), pp.1-28

10 Palliative Care Australia, *State of the Nation 1997: Report of National Census of Palliative Care Services*, June 1998, Palliative Care Australia

A review of the literature reveals much empirical evidence on the process of grieving and its outcomes for the bereaved. There are also many descriptive and evaluative studies of particular interventions and programs. However there are few studies which examine the provision of bereavement support by palliative care services or evaluate how component activities combine to provide an effective program. A selection of the literature available is listed in Appendix A while a more comprehensive bibliography, developed as a resource for further reading, is available as a supplement to this report.<sup>11</sup>

The design of this study rested on two premises. First, the expertise of palliative care service providers, particularly those already providing bereavement support programs, is considered to be an invaluable resource for increasing existing levels of knowledge of appropriate and effective practice. Second, by consulting all palliative care service providers in Australia it was hoped that a consensus would emerge that would be understood and supported by those providers.

For these reasons the study involved two stages. In the first exploratory stage of the study, palliative care service providers and other stakeholders gave their opinions on the importance of specified components of bereavement support programs for palliative care services. They also made detailed recommendations about some of those components.

In the second stage of the study, palliative care service providers commented on the set of principles derived from their responses to the first stage. They were asked to give their opinion as to whether or not each principle should be used to define a minimum bereavement support program applicable to all palliative care services in Australia. The opportunity was also taken to seek more information about risk assessment procedures for identifying people needing services outside the scope of bereavement support.

The following sections describe in detail the two stages of the study.

For the purpose of the study, the term bereavement support program was defined<sup>12</sup> as referring to "a formally specified set of procedures carried out following the death of the patient by designated personnel under the supervision or coordination of a named and qualified staff person (in small palliative care services the same person may fulfil both roles)."

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<sup>11</sup> Palliative Care Australia. *Bereavement, Grief and Bereavement Support: A Bibliography. Supplement to: Principles for the Provision of Bereavement Support by Palliative Care Services in Australia.* November 1998, Palliative Care Australia.

<sup>12</sup> after Lattanzi-Licht, op. cit., pp.9-10

## 4 Stage One - Exploratory Questionnaire

### 4.1 Sampling and Procedure

Several weeks before the first questionnaire was mailed out, an invitation to participate was sent to all service providers listed in the Directory of Hospice and Palliative Care Services in Australia 1997 (n=318) as well as a number of other stakeholders such as the Centre for Grief Education in Victoria and the National Association for Loss and Grief. The background to the study and its aims were outlined and services were asked to nominate a person who would be responsible for input into the process.

The first questionnaire was mailed to all listed palliative care service providers and additional stakeholders. While this mailing was addressed to nominated respondents when available, the decision was made not to exclude other providers, in line with the consultative nature of the project. Similarly, respondents were encouraged to return their questionnaires even after the date specified so as to ensure as many providers as possible were included in the process.

308 questionnaires were sent out and 159 returned, giving a response rate of 52%.

### 4.2 Questionnaire Design

The first questionnaire contained three sections - program activities, additional information and service profile.

#### 4.2.1 Program activities

Program activities comprised a list of twenty-one activities commonly included in bereavement support programs.

The list of activities was derived from the activities included in the National Census of Palliative Care Services carried out by the Australian Association for Hospice and Palliative Care in November 1997<sup>13</sup> and included both activities specified in the census questionnaire and additional activities which were mentioned by palliative care service providers in their responses. Some additional activities were included which were mentioned in the literature<sup>14</sup> but which had not emerged from the census.

The list of activities included items concerning:

- contacts with the bereaved;
- services and activities offered to bereaved people whose grief is normal or uncomplicated;

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<sup>13</sup> ibid

<sup>14</sup> Bromberg, Maria Helena and Irene Higginson, "Bereavement Follow-Up: What Do Palliative Support Teams Actually Do?" *Journal of Palliative Care* 1996 Vol.12 (1): 12-17 and Lattanzi-Licht, Marcia E. "Bereavement Services: Practice and Problems" *Hospice Journal* 1989 Vol.5(1): 1-28.

- the assessment of risk and services offered to the bereaved who are identified as having complicated or crisis grief reactions;
- provision of information to the bereaved and the community;
- data collection; and
- provision of support for staff and volunteers.

Respondents were asked to rate each one on a five-point scale from 1, of no importance, to 5, extremely important/essential. Respondents were asked to indicate the importance of each activity being included in bereavement support programs provided by palliative care services, assuming that reasonable resources are available to support the activity.

#### **4.2.2 Additional information**

Respondents were asked to provide more detail on the following issues:

- essential activities not included in the above list;
- appropriate schedules for telephoning and visiting bereaved families;
- levels of education adequate for staff and volunteers providing bereavement support and bereavement counselling;
- duration of bereavement support for the majority of families; and
- outcomes to be achieved.

#### **4.2.3 Service profile**

Respondents were asked to give the following information about their services:

- location (state or territory and capital city, regional centre and/or rural/remote area)
- number of patients registered in 1996/97
- number of deaths recorded in 1996/97
- current provision of bereavement support according to the definition given.

### **4.3 Analysis**

Of the 308 questionnaires sent out, 125 were received in time to be included in the analysis from which the second questionnaire was derived, a return rate of 41%.

Returns arriving after the final deadline were checked to see that the pattern of responses was similar to those included. Later analysis confirmed that all changes in proportion of respondents rating items essential or very important were less than three percentage points in either direction. The results reported below are those obtained from the initial analysis and are those on which the second questionnaire were based.

Data were analysed using Excel. The information obtained from the open-ended questions in the section "additional information" was coded by content and frequencies were calculated manually.

## 4.4 Results

### 4.4.1 Program activities

Importance ratings were subjected to a frequency analysis. The results are shown in the Table 1. Activities are shown in rank order (1-21) from the activity considered most important to that with the fewest "essential" or "very important" ratings.

**Table 1: Importance Ratings for Program Activities**

Activity	Proportion of respondents rating item as extremely important/essential (5)	Proportion of respondents rating item as extremely important/essential (5) or very important (4)	Importance ranking using proportion of respondents rating item with 4 or 5
Provide support activities for volunteers and staff (eg supervision)	80%	98%	1
Ensure volunteers and staff involved in bereavement support receive education/training (provide training, allocate time, ensure access to resource materials such as journals, etc)	81%	97%	2
Offer counselling for bereaved who are identified as having or who are at risk of complicated or crisis grief reactions	80%	95%	3
Refer to specialists for bereavement follow up where bereaved are identified as having or are at risk of complicated or crisis grief reactions	75%	95%	4
Collect data to evaluate outcomes	47%	82%	5
Provide community education about loss and grief	44%	81%	6
Send letters or notices regarding services available, for example memorial services, group meetings	38%	80%	7
Collect data on provision of bereavement services for planning/budget purposes	46%	79%	8
Use risk assessment tool <u>after death</u> , to identify people with or at risk of complicated grief reactions who may require specialist follow up	50%	79%	9
Staff member who was involved prior to death (eg nurse) makes telephone contact	35%	72%	10
Person trained in bereavement support makes telephone contact	35%	71%	11

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Activity	Proportion of respondents rating item as extremely important/essential (5)	Proportion of respondents rating item as extremely important/essential (5) <u>or</u> very important (4)	Importance ranking using proportion of respondents rating item with 4 or 5
Hold memorial service(s) [please note: this does <u>not</u> include services organised by other organisations eg state palliative care associations]	31%	69%	12
Person trained in bereavement support visits the bereaved	35%	67%	13
Use risk assessment tool <u>before death</u> , to identify people with or at risk of complicated grief reactions who may require specialist follow up	39%	67%	14
Send card on first anniversary of death	33%	64%	15
Organise/facilitate support groups or courses on grieving	27%	62%	16
Staff member who was involved prior to death (eg nurse) visits the bereaved	26%	58%	17
Offer counselling for bereaved people whose grief is normal or uncomplicated	22%	46%	18
Provide or send literature on loss and grief	27%	64%	19
Attend funeral	17%	44%	20
Send seasonal card (eg Easter)	2%	6%	21

Telephoning and visiting the bereaved ranked lower in importance than expected (10th to 17th out of 21) and so these items were subjected to further analysis. Offering counselling to or referring the bereaved who are identified as having or who are at risk of complicated or crisis grief reactions were ranked equally (3rd out of 21) and this was also analysed further. The items relating to whether a risk assessment tool should be used before or after death were examined as well. The results of these further analyses are shown in Tables 2 and 3.

**Table 2: Importance of telephone contact compared with visits.**

Combination of activities	Proportion of respondents rating item as extremely important/essential (5)	Proportion of respondents rating item as extremely important/essential (5) <u>or</u> very important (4)
Telephone contact made <u>either</u> by person trained in bereavement support or by staff member who was involved prior to death	57%	92%
Visit made either by person trained in bereavement support or by staff member who was involved prior to death	52%	85%
Telephone contact or visit made <u>either</u> by person trained in bereavement support <u>or</u> by staff member who was involved prior to death	70%	98%

Table 2 shows that if the question of who should make contact with the bereaved had not been included in the list of activities, contact, either by telephone or with a visit, would have ranked among the top five most important activities rather than 10th or 17th.

**Table 3: Importance of counselling compared with referrals for at risk bereaved and importance of risk assessment before compared with after death.**

Combination of activities	Proportion of respondents rating item as extremely important/ essential (5)	Proportion of respondents rating item as extremely important/essential (5) or very important (4)
Offer counselling to or refer to specialists for bereavement follow up where bereaved are identified as having or are at risk of complicated or crisis grief reactions	90%	99%
Use risk assessment tool either before or after death to identify people with or at risk of complicated grief reactions who may require specialised follow-up	54%	82%

Clearly, respondents felt that it was extremely important to ensure that bereaved people who are identified as having or being at risk of complicated or crisis grief reactions are counselled whether by a specialist employed by the palliative care service or by an outside specialist and this would have ranked 1st in importance in the list of activities.

Similarly, using a risk assessment tool to identify such people was also considered important and would have ranked in the top ten most important activities if the question of whether this should be done before or after death was not specified.

These additional analyses were taken into consideration when selecting items for inclusion in the second questionnaire and in specifying the relevant principles.

#### 4.4.2 Additional information

Sixty-eight respondents suggested other activities they considered essential to the delivery of a palliative care bereavement support service. Some responses were judged to cover similar concepts to those already included, either in greater detail or with a slightly different emphasis, and many responses were mentioned only once. It was concluded that the original list, with one exception, was indicative of the range of activities palliative care service providers consider to be part of the provision of bereavement support.

The exception was a focus on particular groups who might be considered as having different needs. Seven respondents thought it essential to provide bereavement support for children, four mentioned adolescents or teenagers, two mentioned young widow(er)s, one mentioned men, one mentioned multicultural groups and one mentioned "specific groups" without specifying who they might be. These responses made up 22% of the total additional activities suggested.

#### 4.4.3 Schedules

Participants were asked to suggest what schedules for telephoning and visiting bereaved families were appropriate in most circumstances; 93% of respondents answered these questions. The range of schedules varied considerably both in the number of telephone calls or visits considered appropriate and when they should be carried out.

The number of telephone calls suggested ranged from one to fifteen. The only generalisations which could be made about their timing was that 52% of respondents suggested a telephone call at the time of the death or within two weeks of the death (46% within one week, 6% within two weeks). 9% of respondents suggested a telephone call at the anniversary of the death.

Some respondents did not suggest a particular schedule but indicated calls should meet the needs of the bereaved; a total of 33% of respondents stressed the importance of meeting individual needs whether they mentioned a particular schedule or not. A small number (4%) indicated that visits were more appropriate than telephone calls.

A similar pattern was found in the responses to the question about visiting the bereaved, with the number of visits ranging from one to ten. A small number of respondents (4%) repeated the schedule they had suggested for telephoning, while 2% suggested the same schedule with either telephone calls or visits suggested as appropriate. Again many respondents (39%) did not suggest a particular schedule but mentioned individual needs or negotiating a schedule with the bereaved.

A smaller number of respondents suggested visits to the bereaved shortly after or within one week of the death compared to those suggesting telephone calls at this time (30% compared with 46%). A higher number suggested visiting the bereaved at the anniversary of the death compared with those suggesting telephone calls (15% compared with 9%).

#### 4.4.4 Duration of program

There was more agreement about the length of time respondents suggested that bereavement support programs should be offered to the majority of families. They were asked to exclude anniversary events such as cards and yearly memorial services when specifying this time. The most common responses are shown in Table 4.

**Table 4: Suggested Duration for Bereavement Support Programs**

Duration of program	Proportion of responses
No limit/depends on need	14%
13 months or more	15%
12 months	42%
6 to 12 months	3%
6 months	12%
Less than 6 months	10%

The majority of respondents (71%) suggested that bereavement support should be offered to the majority of families for an unlimited time or for periods of a year or more.

#### 4.4.5 Education

Participants were asked what level of education is adequate, first for staff and volunteers who provide bereavement support, and second for staff and volunteers who provide bereavement counselling. 96% of respondents gave detailed answers to the first question, 87% to the second.

The majority of respondents clearly distinguished between support and counselling although there were a small number who gave the same answer for both questions. The most common responses are shown in Tables 5 and 6.

**Table 5: Components of Education Required for Staff and Volunteers Involved in Bereavement Support**

Component	Proportion of responses
Education specific to bereavement support or grief and loss	51%
Specific listening or communication skills	19%
General counselling skills	17%
Supervision, debriefing or support required	17%
Ongoing education, eg workshops	15%
Staff and volunteer education differentiated	15%
Skills for assessing risk and making referrals	11%
Training by a qualified professional	8%

**Table 6: Components of Education Adequate for Staff and Volunteers Involved in Bereavement Counselling**

Component	Proportion of responses
Specialised training in bereavement	28%
Counselling course	19%
Tertiary level - counselling	13%
Tertiary level - social work, psychology	5%
Tertiary level - discipline unspecified	9%
Education should be ongoing	11%
Experience in palliative care or bereavement	10%
Supervision required	7%

#### 4.4.6 Outcomes

The final request for additional information asked respondents to list the main outcomes to be achieved through a bereavement support program. A high proportion (90%) of respondents articulated one or more outcomes. Analysis consisted of extracting common concepts and counting the number of times these were mentioned. Results are shown in Table 7.

**Table 7: Concepts Mentioned in Outcome Statements for Bereavement Support**

Concept	Proportion of responses
Return to adjusted living or society	45%
Facilitate or support grieving	38%
Reduce the incidence of complicated grieving or assess and refer those at risk	26%
Normalise the grieving process	22%
Reduce the risk of ill health (mental or physical)	15%
Positive or healthy resolution of grief for the bereaved	11%
Acknowledgement or acceptance of loss by bereaved	11%
Empowerment or outcomes negotiated with client	9%
Peer support	5%
Community awareness and support	5%
Knowledge of local support and resources	5%

## **5 Stage Two - Final Questionnaire**

### **5.1 Sampling and Procedure**

The second questionnaire was sent to all palliative care service providers listed in the Directory of Hospice and Palliative Care Services (1997) and to other services who had returned the first questionnaire. Organisations other than palliative care services who had not responded to the first questionnaire were not included. Two hundred and eighty five questionnaires were sent out and 189 returned, giving a response rate of 68.7%. Participants were urged to respond whether or not they returned the first questionnaire and whether or not they currently offer a bereavement service.

### **5.2 Questionnaire Design**

The second questionnaire also contained three sections - principles for bereavement support programs, risk assessment and service profile (repeated from the first questionnaire).

#### **5.2.1 Principles for bereavement support programs**

Thirty-one principles derived from responses to the first questionnaire were listed and respondents were asked to indicate whether each one should be included in or omitted from a core set of principles which will define a minimum bereavement support program applicable to all palliative care services in Australia.

Principles were grouped under the headings core value, objectives, structure, processes, and outcomes. Space was also indicated for other principles respondents might wish to include.

Shown with each principle was an indication of the level of support given by respondents to the first questionnaire and space was allowed for comments.

Program activities were included in the list of principles if they had been rated essential or very important by at least 75% of respondents to the exploratory questionnaire.

Other principles were derived from the most common responses to open-ended questions in the exploratory questionnaire and from respondents' comments. The cut-off point for inclusion of particular items was lower than for those derived from program activities because respondents had not previously been asked to consider them and so their importance could not be accurately gauged.

Statements of principle and accompanying comments are shown in Table 8.

**Table 8: Principles Included in Second Questionnaire**

Principle	Commentary
The provision of hospice and palliative care services includes grief and bereavement support for the family and other carers during the life of the patient and continuing after death	from the PCA definition of palliative care
Services aim to support the bereaved as they adjust to life without the deceased	mentioned by 41% of respondents
Services aim to assist the bereaved through the normal process of grief	mentioned by 38% of respondents
Services aim to normalise the grieving process	mentioned by 36% of respondents
Services aim to reduce the risk of physical and mental complications associated with grief	mentioned by 41% of respondents
Bereavement support services are offered to the families and carers of all palliative care patients	derives from core value
Bereavement support services are offered to the families and carers for a minimum of twelve months after the death of the patient	when asked how long support should be offered to the majority of families 42% said 12 months, 10% said 13 months, 5% suggested periods longer than 12 months while 14% suggested that it depended on individual need and that there should be no limit; only 13% suggested periods less than 12 months
Services are provided by staff and volunteers who have received specific education in bereavement support, grief and loss	mentioned by 45% of respondents
Services are provided by staff and volunteers who are trained in communication and listening skills	mentioned by 19% of respondents
Services are provided by staff and volunteers who are trained in general counselling skills	mentioned by 17% of respondents
Services are provided by staff and volunteers who have the skills to recognise complicated grief and identify individuals at risk	mentioned by 11% of respondents
Services will offer support appropriate to the particular needs of the bereaved	children and adolescents were mentioned by 11 respondents, other specific groups by 4 and other cultures by 1 respondent - this constitutes 22% of those respondents who suggested additional activities
Specialist bereavement counsellors who offer counselling within the service or to whom the bereaved are referred will have specialised training or experience in bereavement	training mentioned by 27% of respondents; experience mentioned by 10%
Specialist bereavement counsellors who offer counselling within the service or to whom the bereaved are referred will have appropriate tertiary qualifications	tertiary qualifications mentioned by 26% of respondents; counselling qualifications mentioned by 20%
Services will ensure volunteers and staff involved in bereavement support receive ongoing education and training	rated essential by 81% and very important by 19% of response with the importance of the education being ongoing mentioned by 15%
Services will ensure volunteers and staff involved in bereavement support have access to resource materials such as journals	included with education in first questionnaire

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Principle	Commentary
Services will provide supervision and support activities for volunteers and staff involved in bereavement support	rated essential by 80% and very important by 18% of respondents
Services will seek to empower the bereaved by focusing on the particular needs of individuals and coming to an agreement with them before procedures are carried out (eg visiting schedules, risk assessments, etc)	empowerment mentioned by 10% of respondents when specifying outcomes; individual needs mentioned by many with respect to schedules and how long bereavement services should be offered
Services will contact the bereaved within one week of the death	indicated by 60% of respondents
Services will schedule at least two additional contacts with the bereaved	70% of respondents rated either telephone contacts or visits essential while a further 28% rated either as very important; suggested schedules varied considerably but most respondents specified more than two contacts
Services will schedule contact with the bereaved on the anniversary of the death	33% of respondents rated it essential and 32% rated it very important to send a card on the anniversary of the death; in addition many respondents included this anniversary in their schedule of telephone calls or visits
Services will ensure that people with, or at risk of, complicated grief reactions are offered bereavement counselling or referred to specialist bereavement counsellors for follow-up	rated essential by 90% and very important by 9% of respondents; 80% considered it essential to offer counselling while 75% considered it essential to refer
Services will use a risk assessment tool to identify people with, or at risk of, complicated grief reactions	rated essential by 54% and very important by 28% of respondents
Services will begin assessing families and carers for risk as soon as possible after first contact is made with the patient	when asked the ideal time for risk assessment to be started, 37% answered on first contact, admission or registration; 38% answered prior to death or during the last illness; 9% answered both before and after death or ongoing
Services will ensure that the bereaved are informed about services available to them including notices regarding events such as memorial services and group meetings	rated essential by 38% and very important by 41% of respondents
Services will provide education about loss and grief to the community	rated essential by 44% and very important by 36% of respondents
Services will collect data to evaluate outcomes	rated essential by 47% and very important by 35% of respondents
Services will collect data for planning/budget purposes	rated essential by 45% and very important by 33% of respondents
One outcome for bereavement support services will be reduced levels of physical and mental illness resulting from grief	mentioned by 15% of respondents
One outcome for bereavement support services will be reduced numbers of bereaved at risk of complicated grief reactions	mentioned by 26% of respondents
One outcome for bereavement support services will be increased levels of awareness of bereavement issues in the wider community	mentioned by 5% of respondents

### 5.2.2 Risk assessment

Responses to the first questionnaire indicated that palliative care service providers consider risk assessment to be an important component of bereavement support. High importance ratings were given to activities involving the use of a risk assessment tool and to offering counselling or referral to those identified as being at risk. The reduction of risk was also mentioned by many respondents in their outcome statements.

A separate section on risk assessment was thus included with question design following a previous study by Payne and Relf.<sup>15</sup>

Respondents were asked if they currently carried out risk assessments in their service and, if so, how this was done and the format of any risk assessment tools used. They were also asked to indicate which factors were included in the tool(s) used.

## 5.3 Data Entry and Analysis

Data were analysed using Excel.

## 5.4 Results

### 5.4.1 Service characteristics

The section asking for details about their service was completed by 192 respondents.

Respondents were asked in which state their service was located. Results are shown in Table 9.

**Table 9: Characteristics of Respondents - State/Territory**

State/Territory	Number of responses	Proportion of responses
Northern Territory	3	1.6%
New South Wales	63	32.8%
Victoria	43	22.4%
Queensland	30	15.6%
South Australia	23	12.0%
Western Australia	21	10.9%
Tasmania	9	4.7%
Total	192	100.0%

Respondents were asked to classify the area they served. Results are shown in Table 10.

<sup>15</sup> Payne, S A and M Relf, "The assessment of need for bereavement follow-up in palliative and hospice care", *Palliative Medicine* 1994 Vol.8: 291-297.

**Table 10: Characteristics of Respondents - Location of Service**

Location of service	Number of responses	Proportion of responses*
Capital city	71	37.2%
Regional centre	76	39.8%
Rural/remote areas	66	34.6%

\*More than one response allowed; therefore total may add to more than 100%.

Respondents were given a definition of the term bereavement support program and asked whether their service had such a program. The term "bereavement support program" was defined as referring to a formally specified set of procedures carried out following the death of the patient by designated personnel under the supervision or coordination of a named and qualified staff person (in a small palliative care service the same person may fulfil both roles).<sup>16</sup> If services did not have a bereavement support program as defined it was acknowledged that an alternative might be that supportive follow-up is provided as part of normal daily work with this aspect of care not formally acknowledged or funded. Results are shown in Table 11.

**Table 11: Characteristics of Respondents - Bereavement Support Programs**

Bereavement support program	Number of responses	Proportion of responses
Service does not have a bereavement support program as defined	60	32.6%
Service is in the process of developing a bereavement support program as defined	30	16.3%
Service has a bereavement support program as defined	94	51.1%
Total	184	100.0%

In order to gauge the size of respondents' organisations, respondents were asked how many patients were registered with their palliative care service in the year 1 July 1996 to 30 June 1997 and were asked to give an estimate if they were unable to give the exact figure. Respondents were also asked how many deaths were recorded by their palliative care service in the year 1 July 1996 to 30 June 1997 and again, estimates were requested if the exact figure was not known. Organisations were grouped according to size and the results are shown in Tables 12 and 13.

<sup>16</sup> after Lattanzi-Licht, op. cit., pp.9-10

**Table 12: Size of Organisations - Patients Registered**

Number of patients registered	Number of organisations	Proportion of total
0-50	41	24.3%
51-200	62	36.7%
201-500	43	25.4%
> 500	23	13.6%
Total	169	100.0%

**Table 13: Size of Organisations - Deaths**

Number of deaths	Number of organisations	Proportion of total
0-50	62	36.5%
51-200	67	39.4%
201-500	27	15.9%
> 500	14	8.2%
Total	170	100.0%

A comparison was made between different sized organisations to larger organisations were more or less likely to have a bereavement support program as defined. Results are shown in Tables 14 and 15.

**Table 14: Size of Organisations - Patients Registered - and Bereavement Support Program**

Number of patients registered	Proportion of organisations of this size who have or who are developing a bereavement support program	Proportion of organisations of this size who do not have a bereavement support program
0-50	50.0%	50.0%
51-200	73.8%	25.6%
201-500	74.4%	25.6%
> 500	90.9%	9.1%
All organisations reporting patients registered	71.5%	28.5%

**Table 15: Size of Organisations - Deaths - and Bereavement Support Program**

Number of deaths	Proportion of organisations of this size who have or who are developing a bereavement support program	Proportion of organisations of this size who do not have a bereavement support program
0-50	59.0%	41.0%
51-200	70.8%	29.2%
201-500	88.9%	11.1%
> 500	84.6%	15.4%
All organisations reporting patients registered	70.5%	28.5%

It can be seen that the larger palliative care services are more likely to have, or to be developing, a bereavement support program.

#### 5.4.2 Statements of principle

Respondents were asked to indicate whether each statement should be included or omitted from a core set of principles which would define a minimum bereavement support program and which would be applicable to all services in Australia. Table 16 shows the results.

**Table 16: Proportion of Respondents Indicating that Specified Principles Should be Included or Omitted When Defining a Minimum Bereavement Support Program for All Palliative Care Services**

Principle	Include (proportion of respon- dents) %	Omit (proportion of respon- dents) %	Left Blank (proportion of respon- dents) %
The provision of hospice and palliative care services includes grief and bereavement support for the family and other carers during the life of the patient and continuing after death	99.5	0.5	0.0
Services aim to support the bereaved as they adjust to life without the deceased	93.3	5.7	1.0
Services aim to assist the bereaved through the normal process of grief	89.1	10.4	0.5
Services aim to normalise the grieving process	72.5	25.4	2.1
Services aim to reduce the risk of physical and mental complications associated with grief	90.7	7.8	1.6
Bereavement support services are offered to the families and carers of all palliative care patients	97.4	2.1	0.5
Bereavement support services are offered to the families and carers for a minimum of twelve months after the death of the patient	78.8	18.0	3.2
Services are provided by staff and volunteers who have received specific education in bereavement support, grief and loss	97.9	1.6	0.5
Services are provided by staff and volunteers who are trained in communication and listening skills	53.2	44.7	2.1
Services are provided by staff and volunteers who are trained in general counselling skills	31.6	63.7	4.7
Services are provided by staff and volunteers who have the skills to recognise complicated grief and identify individuals at risk	75.8	21.1	3.2
Services will offer support appropriate to the particular needs of the bereaved	84.7	12.6	2.6
Specialist bereavement counsellors who offer counselling within the service or to whom the bereaved are referred will have specialised training or experience in bereavement	79.8	19.2	1.0
Specialist bereavement counsellors who offer counselling within the service or to whom the bereaved are referred will have appropriate tertiary qualifications	41.1	52.1	6.8
Services will ensure volunteers and staff involved in bereavement support receive ongoing education and training	99.5	0.5	0.0

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Principle	Include (proportion of respon- dents) %	Omit (proportion of respon- dents) %	Left Blank (proportion of respon- dents) %
Services will ensure volunteers and staff involved in bereavement support have access to resource materials such as journals	78.8	19.7	1.6
Services will provide supervision and support activities for volunteers and staff involved in bereavement support	98.4	0.0	1.6
Services will seek to empower the bereaved by focusing on the particular needs of individuals and coming to an agreement with them before procedures are carried out (eg visiting schedules, risk assessments, etc)	65.3	30.6	4.1
Services will contact the bereaved within one week of the death	81.9	17.1	1.0
Services will schedule at least two additional contacts with the bereaved	81.3	17.2	1.6
Services will schedule contact with the bereaved on the anniversary of the death	76.6	22.4	1.0
Services will ensure that people with, or at risk of, complicated grief reactions are offered bereavement counselling or referred to specialist bereavement counsellors for follow-up	95.8	1.6	2.6
Services will use a risk assessment tool to identify people with, or at risk of, complicated grief reactions	88.0	9.9	2.1
Services will begin assessing families and carers for risk as soon as possible after first contact is made with the patient	88.0	10.5	1.6
Services will ensure that the bereaved are informed about services available to them including notices regarding events such as memorial services and group meetings	95.8	2.6	1.6
Services will provide education about loss and grief to the community	87.0	11.5	1.6
Services will collect data to evaluate outcomes	94.3	4.7	1.0
Services will collect data for planning/budget purposes	91.6	7.3	1.0
One outcome for bereavement support services will be reduced levels of physical and mental illness resulting from grief	64.9	25.1	9.9
One outcome for bereavement support services will be reduced numbers of bereaved at risk of complicated grief reactions	77.5	16.2	6.3
One outcome for bereavement support services will be increased levels of awareness of bereavement issues in the wider community	74.9	18.8	6.3

## 6 Risk Assessment

182 respondents completed this section of the questionnaire.

A small number (n=15, 8%) reported that they did not carry out risk assessments. The type of assessments carried out by the remainder is shown in Table 17. More than one response was allowed.

**Table 17: How Risk Assessments Are Carried Out**

Risk assessment method	Number of respondents	Proportion of respondents who carry out risk assessments
Informal risk assessment (eg discussion among the service personnel involved)	121	71.6%
Formal risk assessment (eg check list developed by service)	65	38.5%
Standardised risk assessment tool (eg measure validated by research and available to all)	6	3.6%

121 respondents specified the format of the risk assessment tools they used. Results are shown in Table 18. More than one response was allowed so total does not sum to 100%.

**Table 18: Format of Risk Assessment Tool Used**

Format of risk assessment tool	Number of respondents	Proportion of respondents who specified format used
Open-ended questioning	62	51.2%
Check list	65	53.7%
Rating scale (not weighted)	9	7.4%
Weighted rating scale	7	3.8%

These results are similar to those found by Payne and Relf in that most services used open-ended questioning or a check list to assess people at risk<sup>17</sup> Of the 42 assessment forms they analysed, 24 (57%) used open-ended questioning, 14 (33%) used check lists, 1 (2.4%) used an unweighted rating scale and 3 (7.1%) used weighted rating scales.

<sup>17</sup> Payne, S A and M Relf, "The assessment of need for bereavement follow-up in palliative and hospice care" in *Palliative Medicine*, 1994 Vol.8, pp.291-297

Risk assessment tools mentioned by those using a standardised tool (and some using a formal tool) are shown in Table 19.

**Table 19: Risk Assessment Tools Used - Identified by Respondents**

Risk assessment tool indicated
Win/Carrita Bereavement Risk September 1996; amended May 1997 (standardised)
High risk factors for complicated grief from "Treatment of complicated mourning" by Therese A Rando (standardised)
Parkes 1979 & Raphael 1977; Rodney Watts 1987 (formal & standardised)
Developed from C M Parkes (formal)
Modified version of St Christopher's Hospice risk assessment tool (formal)
At Risk Assessment form designed at MEPCA (Vic) in consultation with David Kissane (formal)
Mal McKissop Risk Assessment Tool (formal)
Adaptation of Rando Grief and Mourning States Inventory (formal)
Combination of tools developed by Silver Chain (WA) and Di & Mal McKissop (NSW) (formal)

The factors included in risk assessment tools used are shown in Table 20, both for all respondents and grouped according to the type of tool used.

**Table 20: Factors Included in Risk Assessment Tools Used by Palliative Care Services**

Factor	Proportion of res- pondents using any assessment  %	Proportion of res- using informal assessment  %	Proportion of res- using formal assessment tool  %	Proportion of res- using standard assessment tool  %
	N= 139	N= 121	N=65	N=6
<i>Circumstantial factors</i>				
1. previous loss	89.2	68.6	89.2	66.7
2. dependants	78.4	61.2	76.9	83.3
3. financial position	63.3	46.3	70.8	50.0
4. concurrent life crises	80.6	62.8	75.4	100.0
5. difficult death	82.7	65.3	78.5	83.3
6. housing situation	43.9	33.1	46.2	50.0

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Factor	Proportion of respondents using any assessment %	Proportion of res-using informal assessment %	Proportion of res-using formal assessment tool %	Proportion of res-using standard assessment tool %
7. sudden death	69.1	55.4	63.1	66.7
8. body image issues	34.5	27.3	33.8	50.0
9. death of a child	65.5	52.9	58.5	66.7
<i>Personal factors</i>				
1. previous mental health	81.3	62.8	81.5	66.7
2. anxiety	62.6	46.3	63.1	66.7
3. anger	56.8	45.5	52.3	66.7
4. emotional symptoms	63.3	54.4	58.5	66.7
5. guilt	54.0	43.8	47.7	50.0
6. suicide risk	69.1	55.4	66.2	66.7
7. physical health	52.5	45.5	47.7	50.0
9. drug use	64.7	51.2	67.7	50.0
10. grief	64.7	50.4	69.2	50.0
11. personality	56.8	47.9	44.6	33.3
12. depression	68.3	57.0	64.6	50.0
<i>Social factors</i>				
1. family characteristics	60.4	43.0	60.0	66.7
2. family support	89.9	66.1	90.8	83.3
3. social support	84.2	63.6	86.2	83.3
4. emotional dependence on the deceased	82.7	62.8	83.1	83.3
5. absence/presence at death	55.4	44.6	53.8	83.3
6. awareness of diagnosis	46.8	42.1	38.5	33.3
7. family tree	23.0	19.0	24.6	33.3
8. spiritual support	54.7	43.8	50.8	83.3
9. difficulty in making decisions	41.7	33.9	40.0	16.7
10. marital relationship	69.8	52.1	75.4	83.3
11. self-care difficulties	51.8	43.8	50.8	33.3
12. member of caring profession	24.5	24.0	13.8	33.3

## 7 Conclusion

### 7.1 Principles

The following principles have been selected from the set presented in the second questionnaire using the criterion that more than 85% of respondents indicated that the principle should be included.

#### **Core Value**

- The provision of hospice and palliative care services includes grief and bereavement support for the patient, family and other carers during the life of the patient and continuing after death

#### **Aims**

- Services aim to support the bereaved as they adjust to life without the deceased
- Services aim to assist the bereaved through the normal process of grief
- Services aim to reduce the risk of physical and mental complications associated with grief

#### **Structure**

- Bereavement support services are offered to the families and carers of all palliative care patients
- Services are provided by staff and volunteers who have received specific education in bereavement support, grief and loss

#### **Processes**

- Services will ensure volunteers and staff involved in bereavement support receive ongoing education and training
- Services will provide supervision and support activities for volunteers and staff involved in bereavement support
- Services will ensure that people with, or at risk of, complicated grief reactions are offered bereavement counselling or referred to specialist bereavement counsellors for follow-up
- Services will use a risk assessment tool to identify people with, or at risk of, complicated grief reactions
- Services will begin assessing families and carers for risk as soon as possible after first contact is made with the patient
- Services will ensure that the bereaved are informed about services available to them including notices regarding events such as memorial services and group meetings
- Services will provide education about loss and grief to the community
- Services will collect data to evaluate outcomes
- Services will collect data for planning/budget purposes

Consensus on outcomes was not reached in the study process, though it would be expected that outcomes would be related to the stated objectives of a bereavement program.

## **7.2 Discussion**

The principles on which a bereavement support service which forms part of a palliative care service should be based, appear to be sensible in terms of underpinning the basic structure and processes of such a service. However, there is not a high level of research that clearly articulates tangible outcomes of bereavement support.

Clearly, palliative care service providers believe that bereavement support is necessary and beneficial and that some standards should be applied to reflect the importance of this. Further, standards would introduce some accountability to this service.

However, it should be noted that the principles for a bereavement support service stated above are broad and not prescriptive about how such a service should be organised and delivered. This is important because it is consistent with the Australian Council on Healthcare Services (ACHS) Evaluation and Quality Improvement Program (EQulP) Guidelines for palliative care provision which also describe broad principles and standards.

This approach allows services to develop according to local community needs, health service configuration, priorities and resources. It would be possible to utilise the consensus view of this study to develop guidelines for bereavement services within the framework of ACHS EQulP.

## **8 Recommendations**

### **PCA recommends that:**

1. the principles for the provision of bereavement support as part of a palliative care service, as set out in 7.1, form the basis of such programs as a minimum standard where bereavement support is funded;
2. the principles are used as a basis for evaluating current service provision through the national census conducted by PCA;
3. the principles form the basis on which standards for bereavement support are developed and form part of the accreditation process of palliative care services;
4. performance indicators be developed to monitor selected processes of bereavement support programs;
5. a research project to determine appropriate outcome measures be conducted; and
6. outcomes be correlated with the structure and processes in order to test the findings of this study.

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