

To see, or not to see: that is the question.
Challenging good-practice bereavement care after a baby is stillborn:
The case in Australia

Recent history of psychosocial postnatal bereavement care

Prior to the 1980s it was considered, in medical circles, best for a mother delivering a stillborn baby to be sent home quickly and told to forget the baby and have another. The baby's delivery was obscured from the mother's view, as best as possible, on the premise that what the eye did not see the heart need not grieve for. On this basis, mothers' grief was often unrecognised or, indeed, considered out of place during her postnatal recovery.

While grief associated with the loss of a baby was recognised in the nursing literature as early as 1962 no articles were published in medical journals until 1970 when Patrick Giles, an obstetrician from WA, heralded this cause from Australia alongside two publications from the US. Stemming from the seminal work of psychiatrists Stanford Lewis and Emmanuel Bourne at the Tavistock Clinic in London, hospital practice following perinatal loss changed from one that attempted to prevent grief, by discouraging parents' contact with the deceased baby, to one that acknowledged the impact as unavoidable and encouraged contact with the baby to facilitate the grief process. A plethora of papers followed in the medical literature recognising the emotional reactions in women after perinatal loss and identifying parents' distress at the lack of recognition of their feelings of loss. The attitudes of those caring for parents at the time were suggested by Condon, (1987) a South Australian psychiatrist, to have a significant impact on parents' emotional outcomes.

Since the 1970s, supportive care aimed at facilitating parents' memories of a deceased baby and thus, their mourning, was reinforced in a wide range of professional publications, supported by parents writing about their own experiences. The importance of seeing and holding a stillborn baby was frequently reported as being associated with better grief outcomes - Callan and Murray (1989) in Queensland and Nicol, **Tompkins, Campbell and Syme** (1986) from WA who also reported that while no mothers regretted seeing and holding their baby, about half who did not were regretful of not having done so. This finding was confirmed by Brabin (1995) from a sample of 255 mothers who had a stillborn baby and 160 of their partners.

Just as the grief-prevention model of care of mothers was based on untested assumptions, the current model, despite its unanimous agreement, however, was based in the main on recommendations from anecdotal evidence on small parent samples from studies with limited designs that have not been adequately assessed on outcome measures.

Over the last 20 years SANDS¹ organisations in all Australian states have reported a resounding shift in the quality of parents' experience and the issues parents bring to SANDS. Far fewer are the complaints about poor postnatal care – of mothers being removed to back rooms and rarely seen by staff, of lack of acknowledgement or even

¹ SANDS = support for parents after early pregnancy and perinatal loss

denial of their emotional reactions and of memorial options not being encouraged. Midwives have broadly embraced training opportunities for the provision of better care after the loss of a baby. Today, it is rare to hear that postnatal care fell short of parents' needs - more often it is the wonderful care from a particular midwife or of the understanding and support from an obstetric practitioner that is reported to a SANDS meeting. The trauma has not changed but the satisfaction with care has.

The UK study

In July 2002, however, The Lancet reported a study by Hughes, Turton, Hopper and Evans that raised expressions of disagreement in four letters published in the November edition of the journal from parents who have suffered stillbirth. Hughes et al. reported that behaviours promoting contact with a stillborn baby - seeing and holding the baby - were associated with poorer emotional outcomes for mothers during the subsequent pregnancy and 12 months after the subsequent baby and an increased prevalence of disorganised attachment in the subsequent infant.

These findings triggered much discussion at the SANDS Australia biennial conference held in Brisbane the following October. The serious concern for those attending this conference, who have promoted the good-practice guidelines of supportive care of parents over the last 20 years, is the possible reversal of their achievements by those who choose to embrace the conclusion of this paper as valid on the grounds that it represents adequate evidence-based research. Indeed, a report from a head hospital social worker indicated that this is the first paper on post-natal care after perinatal loss that obstetricians have been observed to have flagged, embracing the evidence to support their former practices!

In their paper, Hughes et al. concluded that, "Our findings do not match good-practice guidelines, which state that failure to see and hold the dead child could have adverse effects on parents' mourning" (p114). This assertion can be challenged on a number of grounds.

Inconclusive statistical differences?

Although the scores reported by Hughes et al. for depression, anxiety and PTSD² during the third trimester and 12 months after the birth of the subsequent baby are consistently higher for those mothers who held their stillborn baby than for those who only saw the baby who in turn had scores consistently higher than those who did not see or hold their babies few of the individual measures reach statistical difference. Statistical significance was achieved by combining scores on several variables, however, the source of such a difference is clinically inconclusive and of dubious validity.

Differences in supportive care of mothers after a stillbirth in the UK?

A summary of the Hughes et al. sample, contrasted with similar variables from my own study (Brabin 1995) is presented in Table 1. In this earlier work³, parents who delivered a

² Post-traumatic Stress Disorder – a construct phenomenologically different from bereavement and grief measures.

³ Study funded by the Victorian Health Promotion Foundation

stillborn baby between 1984 -1986 were located through four Melbourne and two regional Victorian hospitals and invited to participate in a structured interview with a trained interviewer. Parents were asked about their experience of stillbirth, what they did after the baby was born and how happy they felt at the time of the interview about what they did or didn't do, their experience of the subsequent pregnancy and baby and how they felt about undertaking the interview. In addition to measures of perinatal grief (Perinatal Grief Scale) and parent's assessment of the subsequent child on the Easy/Difficult Subscale of the Child Temperament Questionnaire (LaTrobe Temperament Study), the 28 item version of the General Health Questionnaire (GHQ-28), a frequently used self-report measure of psychological distress, was used to measure emotional health outcomes (anxiety, somatic symptoms, social dysfunction and depression) for parents at the time of the interview.

	Hughes et al. (2002)	Brabin (1995)	
	1-born	1-born	2+-born
Total sample - mothers	65	255	
Stillborn baby	65	119	136
No. mothers subsequent pregnancy	65	225	112 113
No. mothers subsequent baby 12 m	55	221	112 109
*Year of stillbirth (ave)	E 1983-1998 (E 1996)	1844-1986 (1885)	
*Saw stillborn baby	74%	70%	77%
*Saw, not held, stillborn baby	22%	21%	14%
*Held stillborn baby	52%	49%	63%
*Had funeral for stillborn baby	E 56%	50%	57%
Have mementos of stillborn baby	E 68%	38%	48%
Conception after stillborn baby:			
within 5 months	E 25%	32%	27%
within 12 months	51%	66%	70%
between 1 – 4.6 years		34%	30%
* between 1 – 15 years	49%		
At assessment:			
ave age subsequent child (years)	1	4.7	4.5
no. years post loss (ave)	2 - 17 (E 3 years)	3 - 9.5 (6.25 years)	

Table 1
Comparative descriptive data of two studies (“E” signifies an estimate from incomplete data presented in the Hughes et al. study)

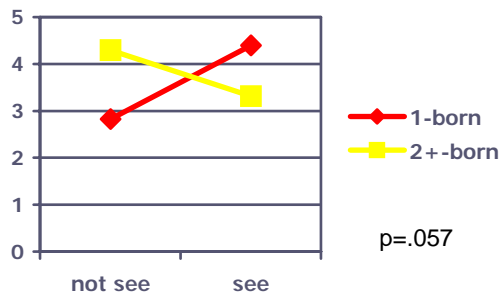
Comparative data on contact options undertaken (see *items in Table 1) indicate clear similarities between the mid 1980s stillbirth experience of the Australian sample and that of the UK sample where most of the deliveries are estimated to have been at least 10 years later. During the 1990s, as a result of the consistent changes in post-natal care promoted by state SANDS organisations and embraced by midwives, in Australia it was rare that parents did not see their babies. This, by contrast, questions the accessibility of supportive post-natal care in UK hospitals, a factor which may have influenced the reported emotional outcomes in the Hughes et al. paper. Furthermore, a range of 15 years for these deliveries further confounds the care received by the parents in their sample.

Assumption that first-born loss is representative of all birth order loss?

The design of the Hughes et al. study included only mothers after first-born loss. In comparison with a mother who has experienced the joy of the birth of a live baby the mother who has not is left with greater feelings of confusion for what she has lost. In SANDS we have observed that the grief of mothers after later-born loss seems to be more intense and more real than for those of mothers whose first baby is stillborn.

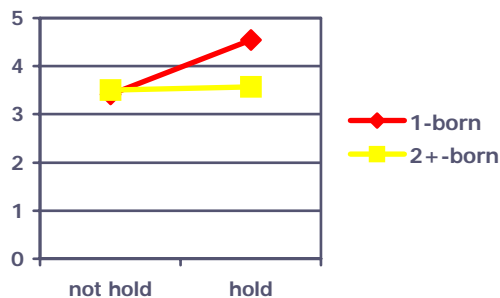
Using GHQ-28 scores, in collaboration with a statistician⁴, I assessed my data for birth order differences using a recursive partitioning form of cluster analysis (Knowledge-SEEKER⁵) which assesses the relationship between the different variables on selected subgroups of the sample. (Further analysis, including analysis of variance, ANOVA, forms part of a more extensive academic report in progress by myself and my collaborators which has been exploring possible explanations for the contradictory findings, as found by Hughes et al., between parents' preferences to see, hold and remember their baby and the emotional outcomes associated with these practices.) From my data it can be concluded that:

- there were no statistical differences in GHQ between mothers after first-born loss who had seen or not seen their infant or between mothers of later-born babies who had seen or not seen their infant (see Graph 1). An ANOVA indicated there was, however, a narrowly missing significant difference ($p=.057$) between seeing and birth order of the baby – seeing the baby appeared to be better for later-born, but worse for first-born, mothers' emotional outcome;
- there were no differences in GHQ scores between holding the baby for each birth order (see Graph 2) and no overall difference was found;



Graph 1

GHQ scores for 255 mothers 6 years after a stillborn baby (1984 - 1986) – See baby for different birth order. (ANOVA, $p=.057$, for two-way interaction between seeing baby and birth order).



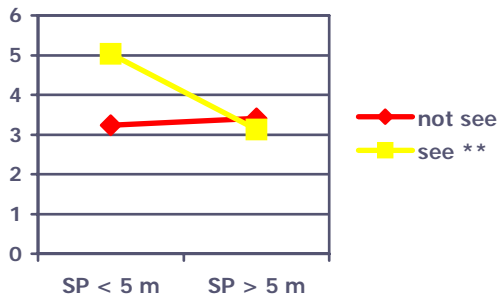
Graph 2

GHQ scores for 255 mothers 6 years after a stillborn baby (1984 - 1986) – Holding the stillborn baby for different birth order.

⁴ Dean P. McKenzie, Department of Psychological Medicine, Monash University

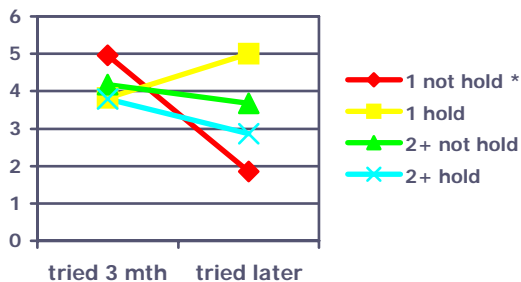
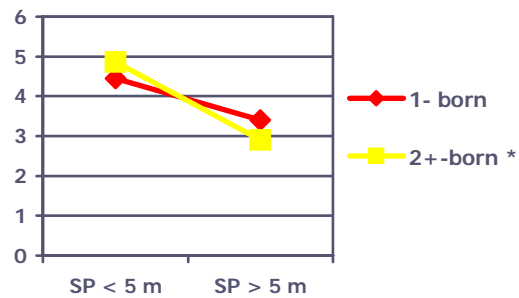
⁵ Angoss Software International, Ottawa, Canada

- seeing the baby was associated with worse outcomes if the subsequent pregnancy occurred within five months (see Graph 3) –
 - although the same pattern occurs across different birth orders, a hasty subsequent pregnancy reached significance only for mothers after later-born loss (see Graph 4); however,
 - trying to conceive within three months was associated with worse outcomes for first-born mothers who did not hold their baby (see Graph 5).



Graph 3
GHQ scores for 255 mothers 6 years after a stillborn baby (1984 - 1986) – Timing of subsequent pregnancy (SP) for mothers as a function of seeing the stillborn baby. (** $p=.01$ for timing of subsequent pregnancy after seeing stillborn baby.)

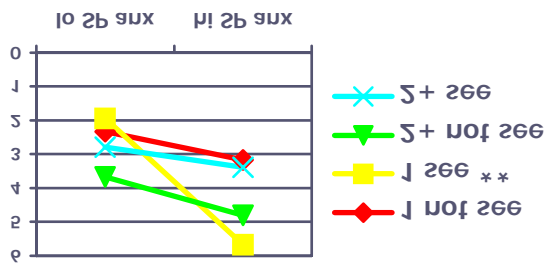
Graph 4
GHQ scores for 255 mothers 6 years after a stillborn baby (1984 - 1986) – Timing of subsequent pregnancy (SP) for different birth order. (* $p<.05$ for timing of subsequent pregnancy after later-born loss)



Graph 5
GHQ scores for 255 mothers 6 years after a stillborn baby (1984 - 1986) – trying to conceive for different birth order as a function of holding the baby. (* $p<.05$ for timing of conception after holding a first-born baby)

Further birth order differences were found, in keeping with Hughes et al.'s findings:

- seeing and holding was associated, after first-born loss only, with increased anxiety in the subsequent pregnancy and a more difficult subsequent child (see Graphs 6, 7) but did not impact on anxiety in the subsequent pregnancy and on subsequent child difficulty after later-born loss;
- Coping with the subsequent child appears to be more difficult after a hasty pregnancy and provides more challenges for mothers after first-born loss (see Graph 8).

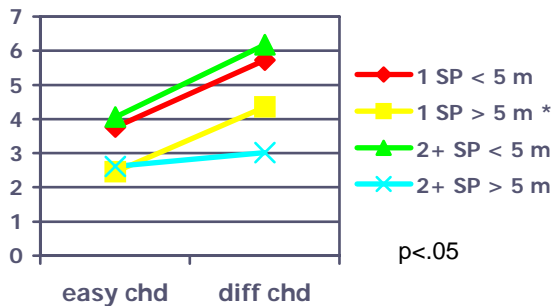
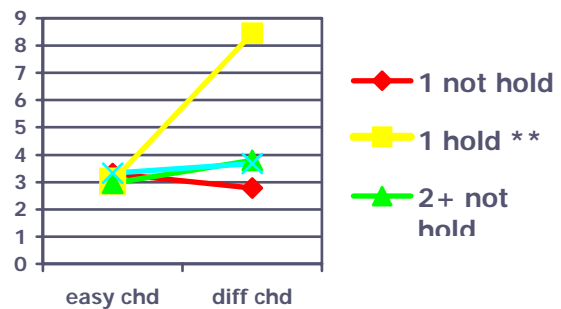


Graph 6

GHQ scores for 255 mothers 6 years after a stillborn baby (1984 - 1986) – anxiety in the subsequent pregnancy (SP) for different birth order as a function of seeing the baby (similar pattern for holding baby). (** p<.01 for difference in subsequent pregnancy anxiety after seeing a first-born baby)

Graph 7

GHQ scores for 255 mothers 6 years after a stillborn baby (1984 - 1986) –subsequent child difficulty for different birth order as a function of holding the baby (similar pattern for seeing baby). (** p<.01 for difference in subsequent child difficulty after holding a first-born baby)

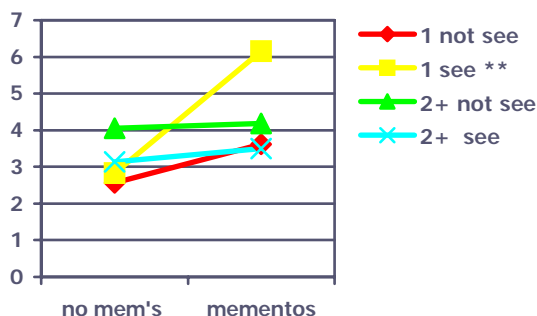


Graph 8

GHQ scores for 255 mothers 6 years after a stillborn baby (1984 - 1986) –subsequent child difficulty for different birth order as a function of timing of the subsequent pregnancy. (* p=.05 for difference in subsequent child difficulty after a hasty subsequent pregnancy for mothers of first-born loss)

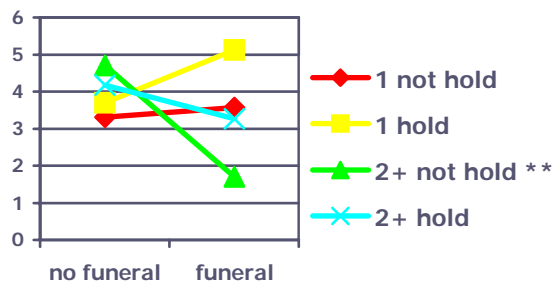
Hughes et al. also reported exploring whether having mementos or a funeral impacted on outcomes but did not report any conclusive findings. We did find differences, again reflecting different impact for the different birth order losses:

- having mementos was associated with worse outcomes for mothers after first-born loss who saw their baby (see Graph 9), with a similar pattern found for mothers who held their baby - an ANOVA indicating a two-way interaction between having mementos and birth order (p<.05) suggested that while having mementos had a negative affect on outcome for mothers after first-born loss this was not so for mothers after later-born loss;



Graph 9

GHQ scores for 255 mothers 6 years after a stillborn baby (1984 - 1986) – have mementos for different birth order and seeing baby (similar pattern for holding baby). (** p<.05 for collecting mementos after seeing baby; ANOVA, p<.05, for two-way interaction between having mementos and birth order.)



Graph 10
GHQ scores for 255 mothers 6 years after a stillborn baby (1984 - 1986) – having a funeral for different birth order as a function of holding the baby. (** p<.01 for the funeral option after not holding a later-born baby)

- having a funeral, however, improved the outcome for mothers after later-born loss, particularly for mothers who did not hold their baby (see Graph 10).

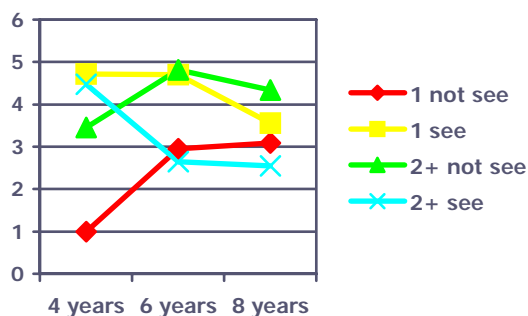
These data are not contrary to the Hughes et al. findings for first-born loss but indicate that this experience differs significantly from that of later-born loss.

Assumption that 12 months after the subsequent delivery that grief is completed?

Studies reported in the grief literature typically assess grief outcomes at 6, 12 months making an implicit assumption that grief outcomes are determined at this stage.

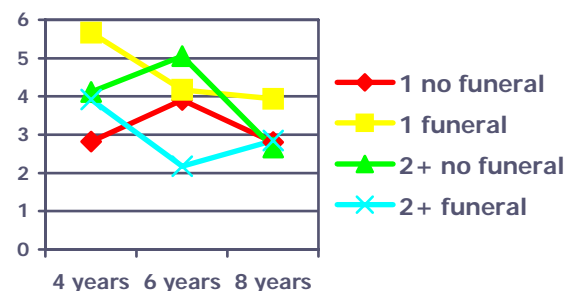
Partitioning my sample into three groups, averaging four, six and eight years since the stillbirth (to be reported in greater detail as part of the more extensive report) again indicates a consistent pattern suggesting (see Graphs 11 – 14):

- higher GHQ scores for mothers, *at four years post loss*, who saw and held their babies, had a funeral, kept mementos and talked about their babies, particularly after first-born loss;
- while GHQ scores for mothers who saw and held their babies, had a funeral, kept mementos and talked about their babies followed a consistently reducing trend over time, scores for mothers who did not see and hold their babies, did not have a funeral, not keep mementos or not talk about their baby were generally *greater* at six years post loss, but more so after later-born loss;

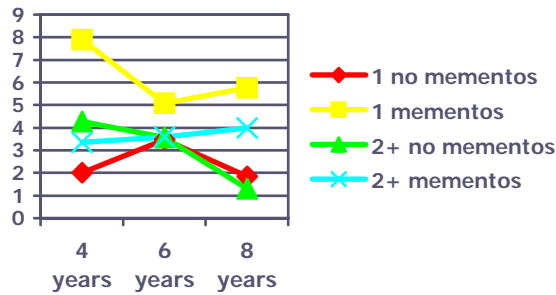


Graph 11
GHQ scores for 255 mothers after a stillborn baby (1984 - 1986) – see baby for different birth order as a function of time since stillbirth (similar pattern for holding baby).

Graph 12
GHQ scores for 255 mothers after a stillborn baby (1984 - 1986) – having a funeral for different birth order as a function of time since stillbirth.

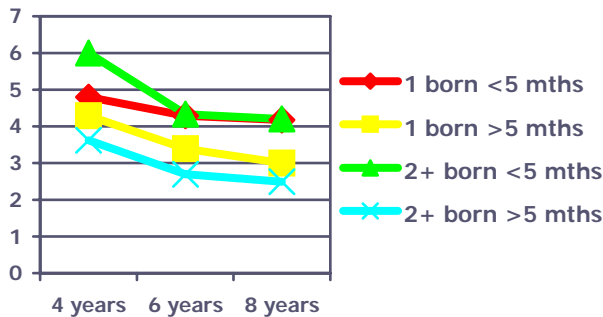
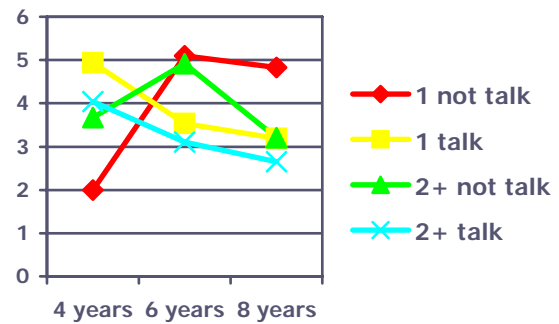


- having mementos (Graph 13) also appears to reduce the pattern of improvement between six and eight years, maintaining mothers' emotional outcomes over this time period;
- Graph 15 suggests that a hasty subsequent pregnancy is associated with consistently elevated GHQ scores regardless of birth order.



Graph 13
GHQ scores for 255 mothers after a stillborn baby (1984 - 1986) – having mementos for different birth order as a function of time since stillbirth

Graph 14
GHQ scores for 255 mothers after a stillborn baby (1984 - 1986) – talking about the baby for different birth order as a function of time since stillbirth.



Graph 15
GHQ scores for 255 mothers after a stillborn baby (1984 - 1986) – timing of subsequent pregnancy (SP) for different birth order as a function of time since stillbirth.

Conclusions

Seeing and holding a stillborn baby, having a funeral and keeping mementos, providing a focus to talk about the baby, are clearly associated with initially elevated emotional outcomes as a result of facilitating grief. Having another baby quickly, implicated as a grief avoidance strategy, appears to be associated with consistently elevated GHQ levels, particularly after seeing the stillborn baby. With no prior experience of parenting coping with the subsequent pregnancy and baby is more difficult for mothers after first-born loss, particularly if by seeing and holding the stillborn baby their grief experience is compounded by a hasty subsequent pregnancy. However, as time progresses this initial emotional outcome subsides consistently.

For those mothers who did not see, hold, have a funeral, keep mementos or talk about their baby, whose initial GHQ scores were lower than those for whom grief was facilitated (as Hughes et al. found), this was not the case six years post loss where emotional outcome scores were elevated. As has been reported in the literature, these parents, over time, may experience cause to regret what they failed to do for their baby at the time of loss. A delayed grief reaction, which may not be recognised as grief, can lead to greater disruption to family stability at this stage. These data reinforce the goal expressed since 1986 in the latest edition of the SANDS(Vic) book, *Your baby has died.....*, (Brabin, 2003) which provides information encouraging parents to make informed choices in order to help prevent them saying in the future “If only we had known” (p. i).

Keeping mementos appears to result in maintaining memories of the baby and may contribute to a chronic grief reaction for some mothers – a reaction that is, nevertheless, more amenable to therapeutic change than one that is not recognised!

Concerns remain for the subsequent baby. Hughes et al. found more disorganised attachment in infants of mothers who had seen and held their stillborn baby. As more than half their sample, at the 12 month assessment of the subsequent baby, were within three years of their loss my results would suggest that they were still experiencing grief for their previous baby. Assessment of the relationship with the subsequent child for mothers who did not see and hold the stillborn baby may be warranted some years later when many of these mothers may experience a delayed grief reaction! My results consistently indicate that subsequent conception after five months is associated with better outcomes regarding the mothers’ experience of the subsequent child.

Contrary to the interpretation of Hughes et al. regarding the current good-practice guidelines, these data both endorse and define the statement, that *failure to see and hold the dead child could have adverse effects on parents’ mourning... by promoting grief avoidance that can result in delayed mourning.*

The current good-practice guidelines, providing a tangible focus for parent’s grief around the time of the bereavement, giving permission to grieve, are strongly endorsed by parents who have suffered the experience as also observed in the experience of other primate mothers taking some days to relinquish a dead baby. No-one could wish to return to the bad old days when the impact of loss was unrecognised and resulted for many mothers in years of silent suffering unable to talk about their experience.

In Hamlet’s crisis of state he questions the value of living – “*to be or not to be*” - yet resolves his preference for being - “*...rather bear those ills we have than to fly to others that we know not of?*” (Hamlet, Act III, Scene I). For parents the answer may be similar - “to see or not to see” - to see is clearly preferred, despite the ills that it may bring initially, rather than the unknown burden that may, one day in the future, be inflicted.

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In Press: Paper submitted, June 2004, for publication in the Autumn edition of *Grief Matters: the Australian Journal of grief and Bereavement*

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