

Guidelines for Loss Support of Dying Children & Their Families

at BC's Children's & Women's Health Centre and Canuck Place Children's Hospice

Grief begins when a family knows that their child's health is seriously threatened. The words 'anticipatory grief' and 'bereavement' categorize the time prior to and after the child's death. It is recognized that grief/loss support is necessary in the continuum of care and after the child dies. Interventions are guided by the family's process as it changes and evolves. NB: The term Child refers to a fetus, baby, child or youth and the terms Grief &/or Loss Support refer to the care.

Objective: The intent of this document is to ensure that all families receive excellence in care, regardless of the setting, by providing the interdisciplinary care team with a framework to guide practice. The four guidelines that ground the framework are family-centred care; an interdisciplinary model of care; support of anticipatory grief and access to care.

The document will act as a guide for practice within Children's & Women's Health Centre of British Columbia and Canuck Place Children's Hospice. Throughout the organizations, there are many patient care settings that have designed their own specific support programs.

Guideline I – Family-Centred Care

Each family whose child faces imminent death or has died will receive individualized, family-centered grief support.

This is achieved by:

- respecting and honouring the meanings the family attaches to the concept of family
- respecting and honouring the meanings the family attaches to birth and death
- identifying the family's needs, hopes and fears, their expectations and their coping skills
- applying knowledge of the physical, psychological, social, educational and spiritual development of childhood, as required
- recognizing the unique personal, religious and spiritual values and beliefs of the family.

Guideline II – Support of Grief Before the Death of the Child

Parents, siblings and the dying child can experience profound loss and stress during the child's dying process. Grief in siblings and the dying child presents itself in countless ways depending on age, family dynamics and coping skills, stage of growth and development, past experience with death, and the nature and context of the child's illness path and death.

Supporting the grief of the child, parents, siblings and other family members is accomplished by:

- creating an environment in which the child and family feels it is safe to express, or not express, feelings that are often difficult to understand and not easily shared
- in accordance with the child and family's wishes and/or choices, openly acknowledging and discussing the child's imminent or actual death
- helping families to maintain a sense of control and to utilize effective coping strategies by meeting their information needs on all aspects of death and dying
- actively supporting families in discussing death and dying with the family's other children
- helping families plan funeral services, burials &/or other culturally appropriate rituals

- referring families to appropriate community agencies and resources that provide loss support to parents, siblings, and members of the child's extended family and circle of friends
- creating opportunities for families to experience quality of life while the child is dying (school attendance, family outings)

Guideline III – Access to Support

Families who experience the death of a child will have information and available resources to support their losses.

Access means that:

- parents have access to information about bereavement services in their own community
- when required, a communication system is in place to facilitate a continuous flow of information among all members of the interdisciplinary team and the family from the time when they know something is wrong with the health of their child through to bereavement
- families have access to specialized bereavement services such as trauma support, relationship counselling, spiritual and/or cultural issues in their own language, etc.
- there is an opportunity to meet with the care team to clarify/summarize events surrounding the child's death and details of bereavement follow-up. This is documented in the health record. For example, the chart should record the name of the person a family is to contact for the results of an autopsy on their child's body and information about other test results.

Guideline IV – Interdisciplinary Model of Care

Each family who faces the potential or actual death of a child will be supported by an interdisciplinary team. Collaborative decision-making and optimal functioning will be facilitated by ethical, open, honest communication among the child, parents, health care professionals, volunteers and other members of the child's community.

The interdisciplinary team will achieve this by:

- on-going consultation with the family to develop, implement, evaluate and document a plan of grief support
- ensuring consensus about the overall goals of care and the desirability of specific interventions as the child is dying and/or has died. This may include conflict resolution.
- upholding principles of quality care by maintaining the family's right to confidentiality and privacy
- providing ongoing educational, spiritual, psychological and emotional support appropriate to the needs and circumstances of the family and other members of the child's community such as friends, school, community service providers, as appropriate.
- supporting one another by creating a milieu in which each person's own spiritual and religious beliefs and insights related to grief and loss are respected
- assisting members of the team, including the family, to acknowledge their own limitations and grief

References

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Assumptions and Principles Regarding Grief and Bereavement¹

Assumptions	Principles
Grief is normal and is often resolved with one's existing resources.	Since many grievors do not require professional intervention, caregivers will help by simply acknowledging & affirming the process' normalcy.
Grief is experienced in varying combinations of intensity and duration.	At any time in the grieving process, care may be needed and should be accessible.
The problems of the bereaved vary. Grief may be accompanied by serious physical, social, emotional, intellectual, spiritual, and economic disruption.	Grieving & bereaved persons may benefit from the assistance of appropriately trained persons, professional or nonprofessional, skilled in bereavement work, & informed concerning other resources that may be helpful in grief work.
Persons experiencing grief frequently have difficulty coping with all the practical, psychosocial, economic, & religious matters which may influence their functioning.	Persons experiencing grief may benefit from assistance in contacting and accepting support from specialized services dealing with legal, religious, vocational, economic, sexual, and social problems.
Grief can accompany or follow a wide variety of losses, including loss of health, death, divorce, separation, & amputation.	Bereavement care should be considered for a variety of losses.
The experience & expression of grief and the needs that emerge may vary widely from individual to individual. They are subject to many variables, including past experiences, cultural expectations, personal beliefs, and relationships.	When bereavement care is needed, there is no single approach that routinely assists the bereaved. Care may include formal or informal methods such as one-to-one or group counseling, discussion groups, practical help, intensive therapy, self-help groups, & the use of the arts - music, art, & drama.
Despite the fact that loss is painful, it can be a stimulus for growth.	As well as support, bereavement care facilitates personal, psychological, social & spiritual growth.
Bereaved persons may be particularly vulnerable.	Caregivers seek to recognize this vulnerability & assist in protecting the bereaved, helping them to utilize their own personal strengths and supports.
Bereaved persons have differing personal philosophies as well as moral and religious values.	Care for the bereaved respects the individuality of those being supported and incorporates variations in accordance with differing belief systems.
Bereaved persons are often unaware of, or unable to reach out to, community resources which might meet their needs.	Caregivers should provide continuing opportunities for the bereaved to "make connection". Outreach should be included in early follow-up.
The bereaved may become over-reliant on caregivers.	Caregivers should minimize the development of undue dependency.

¹ International Workgroup on Death, Dying, and Bereavement, 1993.

The bereaved may not accept the offer of relationships with individual caregivers.	Caregivers must be nonintrusive and sensitive to the individual desires of the bereaved.
Difficulties arising in bereavement may be predicted prior to, or at the time of, loss.	Care for the bereaved should make use of available predictors.
Rituals and ceremonies of leave-taking (e.g. funerals) allow a loss to be acknowledged in a symbolic and formal way. They provide an opportunity for the expression of feelings as well as personal, spiritual, social, ethnic, and family belief systems in an appropriate setting.	Bereavement care should be compatible with the personal spirituality, religious rituals, and social customs of the bereaved.
Bereaved persons often receive fragmented care which may complicate and disrupt the resolution of grief.	Continuity of program planning and communication among caregivers is important.
Care of the bereaved is usually assigned a low priority in health care planning.	Caregivers must seek concrete ways to develop bereavement care as an integral component of health care through planning, education, training, and implementation.
Caregivers can distance themselves by categorizing bereaved persons with mental disability or illness.	Caregivers must avoid the tendency to be judgmental and the use of terms that imply mental illness or aberration.

FAMILY - Traditional & Non-Traditional Relationships

Issue	Intervention
As a patient approaches death, it may be difficult for family to resolve unfinished business, express feelings, & participate in the care. Such difficulties may add to the emotional burden of the bereaved.	Caregivers should facilitate the participation of family members in the care of the patient and nurture communication and contact between patient and family members.
At times, the needs & ambivalent feelings of individual family members will be in conflict with the needs and desires of others who are emotionally involved.	The patient, family, and others who are emotionally involved may require assistance if they are to recognize and allow their conflicting needs and ambivalent feelings.
The family system and its usual dynamics may be disrupted and changed by the loss of a family member and the ensuing grief.	The caregiver should, when necessary, assist grieving families adapt to the changes in relationships related to the death of their loved one.
The expression of grief by family members is an added source of stress within the family & can be disruptive.	Families may need help to recognize and tolerate differing grieving patterns of members.

Loss of a key family member often results in change in social and/or community status and, thus, deprives the person/family of support groups and networks to which they are accustomed.	Persons or families experiencing loss should have assistance available to make the transition to newly defined roles and to re-enter or develop needed support systems.
When adult family members are struggling with their own acute grief, they are often incapable of providing adequate support to grieving children.	Attention must be paid to meeting the needs of children in a grieving family when the surviving parent(s) is temporarily unable to provide the required support.
Latent or active family problems may surface, intensify, and/or continue and may be further complicated by the death of the family member.	Those caring for grieving family members need to have a basic understanding of human behaviour, family dynamics, and the psychology of grief and bereavement in order to identify needs.
Abrupt termination of relationships with primary health care personnel after the death of a patient may subject bereaved family members to secondary losses.	Post-death follow-up by primary health care personnel is desirable to provide continuity, although they may not continue as central caregivers.

Appendix C

Principles Regarding Children & Bereavement

The death of a child has immediate and long term effects on parents, siblings and the family unit.

The death of a child also affects all others who knew the child, including extended family, other children and teachers.

On their own, children and adolescents often lack the cognitive ability, experiences and resources to deal effectively with death. Without help, they may fail to integrate losses which are certain to happen in their lives in a healthy way. Conversely, with help, these same children can gain wisdom and competency to deal with life constructively.

Children are not little adults. Children do grieve but their grief is shaped by their age and developmental level in addition to the whole range of factors that influence grief.

The range of emotional and behavioural responses that bereaved children experience is highly variable in nature with no specific syndrome that can be considered typical.

Compared to adults, children are at greater risk for trauma if they experience a death that is not resolved because the experience can influence all aspects of their developing emotional health and relationships.

As children grow and develop, they need continued help to "regrieve" the loss as new life situations and intellectual and emotional maturity evoke new aspects of grief. This does not

mean that prior grief work was incompletely carried out but that, at any given stage, children can only resolve the impact of the loss up to the developmental level they have thus far achieved.

The family environment is a powerful influence on children's grief and children depend on their parents for help in reconciling it. Children often suffer more from the loss of parental support than from the death experience itself. Also, a child's ability to grieve depends much on what has been learned from the parent. With help, parents can become an integral part of their child's healing.