

Identifying these myths and the false foundations on which they have been constructed serves here as a way to point out the realities of children's and adolescents' encounters with death. It also leads to a set of challenges to adults that can be turned into guidelines for improved interactions between adults and children or adolescents.

The analysis that follows is organized around five central issues:

1. Do children and adolescents grieve, and how can they be helped?
2. Should children and adolescents take part in experiences associated with the dying of a loved one?
3. Should children and adolescents be permitted to take part in funerals and other commemorative rituals after the death of a loved one?
4. Are dying children aware of their situation and how can they be helped?
5. Do schools have a role to play in assisting children and adolescents with issues related to dying, death, and bereavement?

Issue # 1: "Do Children and Adolescents Grieve, and How Can They be Helped?"

Myths

1. Young children do not grieve.
2. Bereaved children and adolescents do not grieve as deeply as adults.
3. Bereaved children are lucky because they are too young to understand about death.
4. Bereaved children should be protected from the pain and suffering that death engenders in order to maintain the innocence of childhood.
5. Because of their youth and resilience, bereaved children and adolescents are able to easily forget about the death of someone close to them, resolve their grief quickly, and get on with their lives.
6. When considered as groups, children and adolescents understand, experience, and express grief in an identical manner.

Realities

1. All children grieve.

- Even infants experience and react to the absence of familiar voices and the feel of different arms that hold and try to comfort them.
- It is both a cognitive and emotional necessity for children and adolescents to grieve.
- Children and adolescents may experience a multitude of feelings including fear, anxiety, guilt, anger, sadness, relief, isolation, and loneliness.
- Many factors influence the grieving process during childhood and adolescence. These include individual variables (such as the child or adolescent's age, gender, developmental level, cognitive ability, personality, emotional maturity, and personal life experiences); environmental variables (such as the amount and quality of emotional support, the family's communication patterns, and the family's cultural and religious beliefs and practices, as well as the child or adolescent's exposure to popular culture and media); and situational variables (such as the relationship to the deceased person, the nature and timing of the person's death, the survivor's participation in the dying process and post-death rituals).
- Children and adolescents often lack support in their grieving; their grief may be disenfranchised when their losses and their roles as grievers are not recognized, validated, and supported.

2. Children and adolescents express their grief differently than adults.

- Initial reactions of children and adolescents to the death of someone close may not be as immediate or obvious as those of adults; when apparent, some of these reactions may be disturbing to some adults.
- Fear of separation and abandonment are especially common in younger children and even older children and adolescents may express fears of being left alone, isolated, and abandoned after the death of someone close to them.

- Children and adolescents may suppress or avoid their grief when they feel insecure, are concerned about upsetting their parents, and/or do not believe that they have permission to express their feelings.
 - Children and adolescents who suppress or avoid their grief may develop considerable emotional and/or physical difficulties.
 - Other children and adolescents who delay their grief may experience serious emotional and physical reactions later in life.
3. Children are vulnerable and may be at a disadvantage when they are grieving because:
- Children strive to understand events in their own ways but often lack the life experiences that can help them comprehend the death of someone close to them.
 - Many children are limited in their ability to express their emotions verbally and to describe their experiences following the death of someone close.
 - Death is a learning experience for children; as they mature and acquire more information, their understandings of death may evolve and change.
4. Children and adolescents cannot be protected from death.
- Death is often part of the play, games, stories, and music of children and adolescents.
 - Most children and adolescents are exposed to death on a daily basis through television, films, and other media.
 - Many children and adolescents experience the death of an animal, pet, acquaintance, peer, neighbor, friend, and/or relative.
 - Those children and adolescents who are excluded from discussions concerning the death of someone close to them and are not allowed to participate in the funeral or memorial services will likely feel isolated and may try to fill in missing information concerning the death with their own imaginations.

- Lack of information and support concerning an important death in their lives denies bereaved children and adolescents opportunities to choose how to take part or not take part in important personal and family activities.
 - Being isolated and left to their own devices may cause bereaved children and adolescents more anxiety than knowing the truth and may generate resentment as to how they have been treated.
5. The grief of children and adolescents does not have any time limits.
- Children and adolescents' search for meaning concerning the death of a loved one becomes a part of their lives as they mature and acquire more information and understanding.
 - Children and adolescents need to be able to accomplish the tasks of grieving, i.e., to understand what has happened, to express their reactions to loss, to commemorate the life that was lived, and to go on with their lives.
 - Children and adolescents also need to be able to maintain a symbolic connection to the loved one who has died.
6. There are clear developmental differences between children and adolescents in the understanding, experience, and expression of grief.

Challenges

1. To acknowledge that all children and adolescents grieve.
- Recognize that the grief of bereaved children and adolescents is a highly individual, cognitive, and emotional process that is influenced by the interconnection of many internal and external factors.
 - Consider all the factors that may influence the grieving process in any particular child or adolescent.
 - Meet the child or adolescent at his or her level of understanding by taking into account developmental level, personality, and life experiences.

- Match answers and explanations to the bereaved youngster's level of understanding; avoid confusing words, associations, and euphemisms.
 - Realize that bereaved children and adolescents may be open to expression and discussion of the spiritual dimensions of their loss.
 - Take your cues from the child or adolescent: never assume that you know what a particular child or adolescent is thinking and feeling; treat each bereaved child and adolescent individually.
 - Acknowledge and respect differences in the cultural and religious beliefs of a bereaved child or adolescent's family; be careful not to impose your own values and beliefs.
 - Understand the child or adolescent's relationship to the dead person; recognize that not all relationships are positive and that some children and adolescents have ambivalent or conflicting feelings that are difficult to acknowledge, identify, and work through.
 - Pay particular attention to those children and adolescents who have experienced previous traumatic or multiple losses, such as those resulting from domestic violence, drug and alcohol abuse, wars, racial, ethnic, or religious communal conflict, and human-induced or natural disasters.
 - Realize that encounters with death on television and in other media can influence children and adolescents' understandings of death in negative ways by offering little distinction between fantasy and reality, and by suggesting that death is only a temporary condition.
 - Limit exposure to fantasized portrayals of death and its implications in the media, and encourage opportunities for children and adolescents to discuss death-related situations as they arise and express their reactions to such situations.
2. To acknowledge that children and adolescents may express grief differently from adults.
- Do not judge, diminish, or discredit bereaved children and adolescents' thoughts, feelings, and reactions; acknowledge

feelings such as sadness, anger, guilt, fear, confusion, and loneliness. They are normal.

- Facilitate play, artwork, creative writing, and storytelling as natural forums for expressing concerns and feelings; pay attention to the thoughts and feelings portrayed through these media and recognize that they can provide unique and valuable insights into children and adolescents' understandings of death and meanings of their losses.
- Do not expect bereaved children and adolescents to conform to adult customs, funeral rituals, and other practices during bereavement; recognize that many may not know how to react and behave.
- Acknowledge the limited attention span of younger children.
- Avoid burdening older children and adolescents with adult rules and responsibilities.

3. To understand that children and adolescents are vulnerable and may be at a disadvantage during bereavement.

- Recognize that children and adolescents' understandings of death and what death means to them change as they mature and acquire new information.
- Appreciate that children and adolescents may need to ask numerous questions and voice their concerns repeatedly in order to incorporate the meaning of the death of someone close into their present level of understanding.
- Acknowledge that children and adolescents need to review and talk about their death-related experiences; understand that this allows them the opportunity to try to make sense of what happened in the past and fit it into their understanding of what death means to them in the present.
- Encourage opportunities for attendance at peer bereavement support groups. Recognize that participation can help with self-expression, peer support, understanding the grief process, and coping with difficult issues that may otherwise linger into adulthood.

4. To assist children and adolescents to develop the tools that they need to understand death and what the loss means to them.

- Use “teachable moments”; do not postpone death education until there is an immediate crisis; use unanticipated opportunities for learning that arise out of ordinary daily living experiences; take advantage of books, storytelling, and other learning materials that introduce and discuss death-related issues.
 - Encourage families to establish and maintain an open pattern of communication that facilitates opportunities for children and adolescents to ask questions and voice concerns when they are ready.
 - Use “nurturing moments” to listen quietly and support.
 - Be available and willing to take the time to be with bereaved children and adolescents.
 - Be willing to learn from bereaved children and adolescents.
 - Provide support and reassurance.
 - Strive to maintain a stable environment by limiting additional changes in the routine of a bereaved child or adolescent.
 - Be honest; answer children and adolescents’ questions and address their concerns directly; accept the fact that adults do not have all the answers but that they have the ability to give responses that provide support, reassurance, and security.
 - Share your grief; provide role models that encourage the expression of grief.
 - Prepare bereaved children and adolescents for what to expect after a death and offer choices concerning their degree of involvement in the funeral preparations and service; provide them with the option to change their minds concerning their degree of involvement.
5. To acknowledge that grief has no time limits and that the death of someone close can have a lasting impact on bereaved children and adolescents.
- Help bereaved children and adolescents accomplish the tasks of grieving.
 - Encourage the use of rituals that commemorate the life of the deceased.

- Over time, help bereaved children and adolescents maintain a connection to the loved one who has died; leave the doors of communication open and encourage the continued use of rituals that help to legitimize and maintain their connection to the deceased person.
6. To identify the differences between children and adolescents in their understanding, experience, and expression of grief.

Issue #2: “Should Children and Adolescents Take Part in Experiences Associated with the Dying of a Loved One?”

Myths

1. Children and adolescents cannot understand and will inevitably be bewildered by the experience of being with a loved one who is dying.
2. Children and adolescents will be permanently traumatized by their last encounters with a dying person; they will be upset by the appearance and/or behavior of that person prior to death.
3. Children and adolescents’ memories will be overshadowed by their experiences with a dying person; happy or good times will not be remembered.
4. Children and adolescents should be protected from the experience of seeing a loved one die.

Realities

1. Children and adolescents need to try to understand or make sense of their experiences.
 - Children and adolescents will seek information, ask questions, and develop interpretations concerning dying experiences at a level that is appropriate for their understanding.
 - Involvement in the dying process of a loved person may help children and adolescents learn that dying and death are essential parts of life.

2. Children and adolescents will remember the experience of being with a loved one who is dying, but it may well be with fondness and enhanced self-esteem because they were respected enough by other family members so they could become involved.
3. Children and adolescents can learn new values about life and about relating to others through their presence or participation in the care of a loved one who is dying.
 - Children and adolescents can be with a loved one who is dying and spend many very precious moments with that person.
4. At a later stage of their development, children and adolescents may resent their exclusion if they are prevented from participating in the care or support of a loved one who is dying.
 - Appropriate involvements with a loved one who is dying will assist children and adolescents when they begin to grieve, either before or after the death.

Challenges

1. To assess the child or adolescent's understanding of what is happening.
 - To prepare a child or adolescent, insofar as that is possible, for what he or she will encounter in the course of being with a loved one who is dying.
2. To extend adequate age-appropriate, information, support, and reassurance, and to be alert to cues provided as to how the child or adolescent is coping with the experience.
 - To recognize signs of grieving, allow a child or adolescent time to ask questions, and listen carefully to obvious as well as latent concern(s).
 - To provide information, support, and reassurance that a child or adolescent may need to cope with his or her experiences.

3. To acknowledge the child or adolescent's achievements in coping with the experience and to help enhance self-esteem as he or she travels through this difficult journey.
 - To help the child or adolescent understand or make sense of his or her experiences, using existing resources of all types as needed.
4. To allow the child or adolescent to be as involved as he or she wishes in the experience, neither protecting the child or adolescent from the experience nor forcing him or her into a situation from which he or she wants to retreat.
 - To enable the child or adolescent to live his or her life in a balance of normal activities, play, school, and involvement with the loved one who is dying.

Issue #3: "Should Children and Adolescents be Permitted to Take Part in Funerals and Other Commemorative Rituals After the Death of a Loved One?"

Myths

1. Children and adolescents should not be permitted to take part in funerals and other commemorative rituals after the death of a loved one.
2. When children and adolescents are permitted to take part in funerals and other commemorative rituals after the death of a loved one, their participation should be limited and they should not be permitted to observe adults expressing strong emotions at such events.
3. Adults know better than children or adolescents what to do after the death of a loved one and should make decisions about participating in funerals and other commemorative rituals on behalf of and in the best interests of the particular youngster.

Realities

1. Children and adolescents can benefit in meaningful ways both by assisting with the planning and by attending or participating

in funerals and other commemorative rituals after the death of a loved one.

- Attending and participating in funerals and other commemorative rituals after the death of a loved one can give children and adolescents opportunities to ask questions and to talk about their feelings.
 - Observing ways in which adults react to and cope with the death of a loved one during a funeral or other commemorative rituals can help to legitimize and guide bereaved children and adolescents in their own grief and mourning.
2. Attending and participating in funerals and other commemorative rituals after the death of a loved one can enable children and adolescents to experience the support received from others and help to overcome feelings of isolation and bewilderment often experienced by grieving youngsters.
 - One way in which bereaved children and adolescents can begin to recapture a measure of autonomy and control in their own lives after the death of a loved one is to take part in planning funerals and other commemorative rituals, and to help determine the extent and manner in which they will or will not be involved in such events.
 3. Children and adolescents who are excluded by adults from funerals and other commemorative rituals after the death of a loved one or forced to participate in such events against their will, may experience immediate and long-term difficulties.

Challenges

1. To assess an individual child or adolescent's understanding of funerals or other commemorative rituals after the death of a loved one.
2. To encourage (but not force) a child or adolescent to take part in appropriate ways in a funeral or other commemorative ritual after the death of a loved one.

- To provide a child or adolescent with information about what is expected to happen during the ritual event.
 - To support a child or adolescent's decision concerning whether or not and how he or she wishes to take part in a funeral or other commemorative ritual after the death of a loved one, and to provide options for the child or adolescent to leave the site if he or she feels uneasy or overwhelmed.
 - When appropriate, to develop alternative rituals or to restructure adult practices in ways that best serve the needs of bereaved children and adolescents.
3. To help the bereaved child or adolescent build on or develop a value framework within which he or she can integrate his or her encounter with loss, grief, and mourning, and to encourage that child or adolescent to go on with productive living.

Issue # 4: "Are Dying Children Aware of Their Situation and How Can They Be Helped?"

Myths

1. Dying children less than 10 years of age are unaware they are dying.
2. Dying children, because they are unaware, do not experience anxiety.
3. Dying children do not communicate their fears and concerns.
4. Dying children have no concerns for themselves or for others.
5. Dying children's questions are best left unanswered.

Realities

1. Dying children know they are dying.
 - Pioneering studies conducted in the late 1960s and early 1970s showed convincingly that dying children are aware of their situation and that they experience fear, loneliness, and anxiety.

- These studies also showed that denial and protectiveness by adults are ineffective in preventing these children from experiencing anxiety or in keeping their diagnosis and probable prognosis from them.
 - Children suffering from a life-threatening illness acquire a concept of death in very different circumstances to children who are well.
 - Children who are dying will have acquired awareness and concepts far in advance of what one might assume from their age.
 - Children who are about to die are aware of their imminent death and frequently give a message to their families that such is the case.
2. Dying children experience fear, loneliness, and anxiety.
- Anxiety about death is an issue for all children with a life-threatening illness, whether or not they eventually survive.
 - Dying children have the same emotional needs as all children regardless of their state of health.
 - Dying children have additional needs that result from their experiences of and reactions to illness and hospitalizations, as well as those arising from their concept of death.
 - Dying children fear separation from their parents and loved ones, and sense and respond strongly to the level of anxiety surrounding them.
 - Dying children are helped by the provision of age-appropriate information.
3. Dying children may choose not to communicate but are competent to communicate clearly.
- Dying children who do not wish to discuss painful matters and seemingly put on a brave front may, in fact, be seeking to protect their loved ones from further emotional turmoil for which they may feel responsible.
 - Young children may communicate their worries directly, indirectly, or symbolically.

- Dying children usually know that they are dying; if a child asks the question, “Am I dying?”, he or she has chosen the particular person to ask and is seeking confirmation that it is safe to discuss the issue with that person.
4. Dying children worry about themselves and about others.
- Children who are terminally ill will commonly take steps to put their affairs in order.
 - A common concern of dying children is that they will be forgotten after their death.
 - Dying children often leave messages for their parents, family members and friends, and (depending on their age and cultural background) may assist in the planning of their funerals and the selection of their burial site.
 - Dying children and adolescents worry about the pain and sadness their parents and loved ones will experience after their death.
5. Dying children’s questions need honest answers.
- If a child asks, “Am I going to die?”, the wisest and best response is to be honest.
 - How one replies and the words one uses will vary greatly because the details of each child’s situation and management and the relationship with the caregiver make every case unique.
 - One needs to be aware that behind the question, “Am I going to die?”, a child may indirectly be expressing other concerns, such as “Will you give up on me?”, “Am I going to be in pain?”, “Will I be able to go home?”

Challenges

1. To acknowledge that dying children know they are dying.
- Caregivers who adhere to the conviction that dying children do not understand death and do not experience anxiety about death should reappraise objectively their convictions in light of currently available knowledge in this area.

2. To acknowledge that dying children may experience fear, loneliness, and anxiety.
 - Acknowledge that it may be difficult for young children to express their fears.
 - Acknowledge that a child's perception and understanding of death will be influenced by chronological age, developmental level, individual personality, past experiences with death and loss, and the family's cultural values or religious beliefs.
 - At the time of transition to palliative care and thereafter, health care professionals should be attentive to and include the ill child or adolescent in at least some of the discussions about further management; being included in such discussions will help decrease fear, loneliness, and anxiety.
 - With the consent of the parents, one should consult directly with children over 5 or 6 years of age at this important time.
3. To be attentive to the communications of dying children.
 - Health care professionals should strive to be attentive to a dying child's verbal and nonverbal communications, and seek, where possible, to lessen the child's anxiety.
 - Before proceeding with communication, a caregiver should ascertain the child's own perception of the situation, taking into account the child's own developmental level and life experiences.
4. To acknowledge and address the concerns of dying children.
 - Clarify reality; children often have difficulty distinguishing between reality and fantasy; a common fantasy of sick children is that of being responsible for their own illness; thus, hospital admissions and medical procedures may be interpreted as punishment.
 - Encourage the expression of feelings; when children are allowed to express their anger, sadness, and anxiety they are able to examine these feelings, place them in perspective, and gain control over them.

- Music, art, drama, and similar expressive therapies can all be used for effective communication by and with a child.
- Promote self-esteem through mastery; the self-esteem of a child with a life-threatening illness is threatened by pain, frustration, deprivation, changes in body image, and the possibility of death.
- Provide maximum physical relief and comfort for all children with a life-threatening illness, including infants too young to have a concept of death.
- Issues of concern to dying children may vary somewhat with development; for example, younger children often fear the separation from parents and other loved ones that death entails, whereas older children typically fear abandonment, destruction, and body mutilation.
- Be open and honest, provide truthful explanations of symptoms and their management, and foster the child's sense of control over his or her deteriorating body.
- Maintain access to peers.

5. To be honest with dying children.

- If a child asks, "Am I dying?", to not answer the question or to give a dishonest answer deprives the child of a valuable opportunity for communication.
- The important thing is to be honest and stay with the child to deal with whatever specific concerns he or she may mention next.
- If a caregiver feels ill-equipped or too uncomfortable to work directly with a dying child, then it may be better to work just with the child's parents or family, and arrange for a willing colleague approved by the child to work directly with the child.

Issue #5: "Do Schools Have a Role to Play in Assisting Children and Adolescents with Issues Related to Dying, Death, and Bereavement?"

Myths

1. There is no need for children and adolescents to know about

- death and grief, because youth is a time free of pain and sorrow.
2. Nothing can prepare a child or adolescent for death-related loss; when death intrudes children and adolescents should be shielded from sorrow by caring adults, including teachers.
 3. Death education is poorly defined, unnecessary for young people, has no place in schools, and can be harmful to students; parents do not want their children to become involved with death education programs.
 4. Teachers are neither competent nor prepared to intervene with a grieving student.
 5. Children with life-threatening illnesses no longer belong in the classroom because their presence may negatively affect their classmates; teachers and classmates no longer have a role in the life of a child with a life-threatening illness.
 6. Programs of suicide prevention have no place in schools.

Realities

1. No time in life can be guaranteed to be free from all encounters with death, loss, and grief; many events in life may lead children and adolescents to think about or form attitudes related to death.
2. Children and adolescents are always better off when they confront death and other difficult challenges in life from a foundation of prior preparation; misguided protectionism in the form of efforts to shield children and adolescents from death-related events with which they will need to learn to cope is no substitute for a sensitive and caring program of prior preparation.
3. Informal death education goes on constantly for children. Formal death education programs provide a structured framework in schools, which can be used to benefit students, their families, and staff members. Educators are called on to assist bereaved students when a death occurs.
 - A death of a loved one or other significant loss can change student behavior and inhibit the learning process; teachers and school staff members can play an important role in helping students to understand and adjust to these changes.

- Children can learn about death and grief, and can be helped to acquire coping strategies for use when such losses occur; children can learn effective ways to cope with their fears, anxieties, jealousies, anger, and loneliness.
 - Death education can be controversial with some parents and teachers but is welcomed by others; staff members, administrators, and parents need to cooperate and prepare before a death occurs to help grieving students.
 - Death education programs include three main categories: ongoing programs that help prepare children for the losses they will encounter in life, intervention programs to use when a death or other crisis affects the school community, and post-vention programs for follow-up and continued support of members of the school community.
 - Rituals within a class or school help bring the school community together to support grieving members when a death occurs.
4. Teachers are professionals with the experience and preparation to work with children and adolescents.
- Courses and staff development programs have been developed in some communities for teachers and the number of educators prepared to offer such assistance is growing.
 - Graduate institutions, medical centers, funeral service programs, and self-help/mutual support organizations offer materials, presentations, and guidance to inform and train educators.
 - Adequate preparation for teachers and administrators must include both cognitive and emotional dimensions, as well as an examination of personal concerns related to death, dying, and bereavement.
5. Maintaining ties with school is important for children with a life-threatening illness, their classmates, and their teachers.
- There are special difficulties when a student is coping with a life-threatening illness, such as irregular attendance, changes in body image (e.g., hair loss, loss of weight, weight gain, loss

of a limb, or disfigurement from surgery or other treatment), the need for treatment during school hours, inability to participate fully in class activities (such as strenuous games or sports), and remaining involved in class lessons and assignments while absent from school.

6. Suicide prevention programs for older children and adolescents have been shown to play a positive role in reducing the number of attempted and completed suicides among students.
 - Such programs have educated students about the topic of suicide and suicide prevention.
 - As a result of these programs, some students have developed peer support networks, assisted counselors in identifying at-risk students, and helped classmates to seek professional assistance.

Challenges

1. To assist teachers to understand better the ways in which a death can affect their students.
2. To help teachers and parents identify and assist students who are coping with grief and loss in ways that may interfere with the learning process.
3. To minimize difficulties experienced by students who are coping with death and loss through a plan of action that facilitates cooperation among educators, parents, and health care professionals; such plans need to be individualized to suit the particular child and his or her situation.
4. To develop and implement death education programs for educators, students, and their families.
 - Administrators and teachers need to be sensitive to the needs of students and the concerns of parents when developing and implementing death education programs.
 - Death education programs should address preparation by developing and implementing student courses, staff and parent education programs, crisis preparation plans, and clear lines of communication; intervention by implementing a

plan of action for use in the school community during and immediately after a death or similar crisis; and follow-up by developing appropriate rituals for staff and students, and by offering long-term support for members of the school community after the immediate crisis.

5. To increase the availability and quality of courses and programs to prepare members of the school community to identify and meet the needs of their students.
6. To maintain, expand, and monitor suicide prevention programs in order to serve the needs of students and prevent proposed interventions from aggravating current situations.
 - Such programs can serve to sensitize both the schools and their communities concerning the issues they face and the resources they possess.
 - Such programs work most effectively when they draw on school, family, and community members (e.g., police, fire, and health care professionals, as well as religious, spiritual, and political leaders).

Developed by the Work Group on Palliative Care for Children of the International Work Group on Death, Dying, and Bereavement.

David W. Adams, M.S.W. (Canada)
Charles A. Corr, Ph.D. (U.S.A.)
Betty Davies, Ph.D., R.N. (Canada), *Chairperson*
Eleanor Deveau, M.S.N. (Canada)
L. L. de Veber, M.D. (Canada)
Ida M. Martinson, Ph.D., R.N. (Hong Kong)
Sister Margaret Noone (Australia)
Danai Papadatou, Ph.D. (Greece)
Eleanor Pask, Ed.D., M.Sc.N., R.N. (Canada)
Michael M. Stevens, M.D. (Australia)
Robert G. Stevenson, Ed.D. (U.S.A.)