

# Strategies For Teachers, Classmates, And Parents of Seriously Ill Special-Needs Children



**Patricia Ainsa\***

*Department of Counselling and Special Education, USA*

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**\*Corresponding author:** Patricia Ainsa Department of Counselling and Special Education, University of Texas El Paso USA, tainsa@utep.edu

## Abstract

Forty-three years ago, research on teaching strategies focusing on terminally ill children was reported. This article focuses on the teachers, parents, and classmates of seriously ill special-needs children. Special needs with an added challenge of severe illness and/or terminal illness presents both emotional and curricular burdens on the family, classmates, and Special Education teacher. Four at-risk children, two in early childhood and two in early elementary grades were studied due to their special circumstances in an inclusion Special Education classroom setting. Teacher, peer, student, and family insights were studied, and interview comments were recorded for the purpose of sharing with other Special Education teachers in similar circumstances.

**Keywords:** leukemia; Cancer; Cystic Fibrosis; Muscular Dystrophy; Terminal Illness.

## Introduction

Forty-three years ago, I researched and reported on teaching strategies for terminally ill children. This article focuses on the teachers, parents, and classmates of seriously ill special-needs children. Four at-risk children, two in early childhood and two in early elementary grades were studied due to their special circumstances in an inclusion Special Education classroom setting. Strategies are presented and discussed and reactions from teachers and parents, seriously ill children, and classmates are presented for further reflection.

## Review of Literature

### Children's Perceptions of Death

In the Oxford Textbook of Palliative Care for Children, Hain et.al [1] discuss children's views of death. Studies, past and present, demonstrate the need to understand children's views and approaches to talking and dealing with death in the context of their family, the cultures, and communities in which they live, their religious practices, and their belief systems. Children's views of death manifest in art, play, conversations, and senses. When ill children do engage with their parents in a conversation about

death, they are careful to express it in a way that their parents can handle and not get upset. Since the child's view of death is somewhat fluid, teachers and parents should listen first and take cues from the child. Conversation should be easily understood by the child and the child's questions should certainly be responded to.

A child in the preschool years has had exposure to death through the death of a pet a relative or through watching television. Although the concept is immature at this stage because the 3 to 5-year-old children do not believe in the finality of death it is more like sleep and temporary. Children must be reassured that death is not a consequence of bad behaviour. Between the ages of six and 12, elementary children are aware that death is universal and inevitable. This age group wants to know about illness and investigate its causes. Children deserve truth and sometimes cannot talk to their parents without the situation becoming very emotional. Some children will want to talk to their classroom teachers. Goldman [1] suggests that some of the emotions and behaviors exhibited by a student who is dying include Shock and disbelief, crying and loneliness panic, guilt, hostility, resistance and lack of cooperation, reconciliation and initial acceptance,

full acceptance. Bessell [2] interviewed children with chronic illness about their needs. Children stated that feeling normal was enhanced by being able to attend school. Understanding classmates and teachers were deemed helpful. Even when children had to go to a homebound situation, being kept in the loop of classroom activities and happenings made them feel included.

## Teachers Perceptions of Death and Grief

With more children with life-threatening conditions (leukemia, cancer, cystic fibrosis, HIV/AIDS, and muscular dystrophy) attending schools, it is plausible that their teachers and supporting staff anticipate their death, which can cause Anticipatory Grief. O'Brien [3].

Although much is written about supporting children and families when a child dies, a search of nursing, medical, psychological, counselling, and educational literature reveals few guidelines for supporting bereaved professionals. Although special education personnel frequently experience grief, the death of a child is not within their normal range of expectations or training, and they often lack substantial training and support to deal with grief O'Brien [3]. Some of the characteristics of anticipatory grief include sadness, tearfulness, fear, anger, loneliness, guilt (survivor guilt), extreme concern, rehearsal of death, and physical problems such as lack of sleep.

The grief experienced by special education after the death of a student is influenced by many factors. Among these determinants of grief are (i) the relationship between the member of staff and the deceased student, (ii) the mode of death of the student, (iii) the age of the deceased impacts the grieving, (iv) the presence of a support system in the staff member's life, (v) the religious, social, ethnic, and cultural background of the member of staff, (vi) the staff member's coping behaviors, and (vii) the staff member's previous experience with loss, (death/divorce/job change etc.) O'Brien [3].

## Parents Perceptions

Parents tend to have clinically recognizable phases which reflect their child's illness. Emotions vary from initial shock and questioning to a family reorganization focusing on the child and his needs. Parents naturally want to help their children, but the emotional involvement becomes a behavioural challenge for them. It can be a great strain to behave naturally openly, honestly, and caring.

## Classmates Perceptions

Other children in the class may experience the death of a pet, friend, or family member. Students desire open communication with family and members of the education staff. Classmates are usually a little fearful of contagion and the same fate happening to them; and therefore, they need support.

## Methods

Four teachers who had attended my classes since 1981 or who had participated in a "Teaching the Terminally Ill Child" workshop asked for help and support when they were teaching special needs children with terminal illness. All parties wished to remain anonymous. Teachers often do not give themselves permission or time to grieve and special education staff may often be required to put their own grief on hold while helping others.

Schools can support staff to cope with the deterioration and death of students through (i) providing in-service grief workshops (ii) developing a grief plan (iii) developing staff support initiatives and (iv) providing guidelines on support for the surviving students after the death of a classmate. Addressing the support needs of the school community could improve job satisfaction and prevent compassion fatigue.

During a workshop, grief should be defined and discussed in its various manifestations. These emotional effects will be different for different individuals. The reality of the loss is initially accepted. After that, working through the pain and sadness is best with the aid of an emotionally supportive social system. Provide opportunities for staff to grieve together. Next, adjusting to the loss and getting to the new normal of not having the deceased person a part of daily life. Moving on means holding on to the memories departed without being prevented from significant relationships with the living. Worden [4].

The plan must include support for all staff as well as support for other students and families and should acknowledge the staff member's role in the life of the child. It is recommended that all staff be involved in the plan's conception to ensure it reflects their preferences and needs. Rituals and Remembrances (Tree Planting or Dedication Benches) can be a part of the plan. The emotional safety policy is to ensure that staff members feel emotionally supported to deal with the unique demands of their work. Invite staff to articulate the type of assistance they need during the initial stages of grief as well as during the extended grief process.

## Supporting Surviving Students

The death of a student must be addressed in the special education classroom, as there are significant consequences for individuals with an intellectual disability if they do not understand dying and death. Fulton [5]. Schools must support their staff in exploring death with students as teachers' comfort with the topic of death has a direct impact upon their ability to provide a positive environment in which children can explore the concepts of death and dying. Using simple language that is factual is recommended for children with learning disabilities. Art, music, or drama can help children with limited expressive skills grieve. Searching behaviour is common with some special needs

children. Accompany a child who is searching for his lost friend to help explain and support his grieving. Most importantly, maintain the same routines. Children feel safer if the same rules apply after death. Helton [6].

## Staff Recommendations

### Anticipatory Grief Guidance

During this time, basic self-care becomes more important. Physical self-care (rest, eat healthy, exercise); emotional self-care (reflection, meditation, amusement, or recreation); cognitive self-care (positive internal dialogue, release tension, no judgement or perfectionism); Relational self-care (supportive personal relationships, management of interpersonal conflict); spiritual self-care (humor, focus on what is important, find meaning). Wolfelt [7].

### Supporting the Seriously Ill Special Needs Child

The child must be reassured that he is loved and will never be abandoned. Literature, as well as creative activities, such as drawing, painting, storytelling, and puppets help to facilitate discussions.

### Intervention

Four students, three teachers, and four families were interviewed about the strategies and needs in the Special Education Classroom. Classroom in-service and all strategies described above for Teachers, Parents, Classmates, and the seriously ill special needs child were reviewed and offered to the persons involved. Support strategies were the most requested intervention for the teachers, and the families. Activities were requested by the students.

### Some suggestions that were most requested follow.

- Considering the child's specific developmental, social, and learning needs, Gaines [8] recommends some suggestions when talking to children.
- Use Real Words. Seriously ill children with special needs often process information in an especially concrete manner. Anticipate the health changes and the next steps in treatment to talk with the child as it is happening. Emotional displays may confuse the children. They need to know emotion is an expression of love, and this must be explained. Accept regression and self-soothing behaviors as the child progresses through the illness.
- Teacher behavior and intervention was classified and personal according to each family's wishes. Some families wanted a more open approach to the illness while others felt that the child's privacy was paramount. The suggestions are included in the discussion section of this paper.
- Strategies

- Strategies for early childhood and elementary special education for the terminally ill student include literature, writing, role playing, play therapy and art projects as well as art therapy.

- Writing: written, language, expresses joy, sadness, death, sickness, in stories and/or diaries. The work does not have to be shared, but the feelings can be dealt with through this written expression.

- Role-playing: a role-playing experience allows children to participate in coping with the situation of death Surrounding death, dying illness, happiness, and sadness.

- Play therapy: play is recognized as providing insight into perceptions feelings and ideas. Unexpressed feelings will surface in place situations.

- Art therapy: crayons, paint, colored chalk, finger paint, and clay should be available so that feelings can be expressed through art if they cannot be expressed verbally.

- Biography: Chochinov [9] suggests helping a child with memoirs-including parts of life that the child considers most important. For example, ask "What did you do that you want your family to remember?"; "Do you want to say anything to anyone?"; "What have you learned that you want to pass along to others? Advice?"; "Is there anything else you want me to write?"

- When a child is in the last days: [10-15] he may want to give gifts to favorite relatives, nurses or friends or classmates to be remembered if the child is too weak to make new ones, previous art projects could be aimed at this goal. Encourage the child to write or dictate [16-20] letters to his favorite people in the spirit of sharing.

## Results

Statements from the students and families and teachers were all incorporated into suggestions to share with Special Education teachers. The percentages indicate the strength of agreement of the interviewees. It was noted that most seriously ill students agreed with their family spokesperson, and many let the speaker speak for them while they nodded.

## Discussion and Suggestions

When a student has cancer, here are some supportive steps which have been verified by early childhood and elementary parents as most helpful follow.

### Behaviour and Policy

Respect the family's decision about sharing of diagnosis, while taking time to learn about treatments and the effects on school performance 100%.

Teachers can give a developmentally appropriate presentation about cancer, including the type of cancer, treatment, and side

effects. They can also dispel myths and misconceptions, and let students know that cancer is not contagious. 50% Listen to concerns and fears and call or visit during absence. Take correspondence or pictures from classmates to the ill child if the diagnosis has been shared with classmates 75%.

Re-entry can be challenging. Before reentry, talk to the student about fears. Medical and parental routines should be enforced 100%.

Provide tutors and adjust lessons and assignments according to energy levels that may vary during illness 50%.

Above all, the student should be treated normally while participating in as many activities as possible. 100%

The percentages above could be due to stages of illness and stages of acceptance and coping on the part of the child's family.

### Most Significant Activity and Strategies

All the interviewees stated that writing and art were the most significant activities and strategies because they were going to outlast the lives of the creators. These activities were stated as most important because they provide a legacy while providing the child with a means of expression. Art was more appropriate for early childhood special education with storytelling about art. Elementary children wanted the writing to stay with their family and be treasured as a permanent remembrance of their lives.

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