

- Please don't ask us if we are over it yet. This is something we will never get all the way over. We will always remember their smiles and giggles just like you would remember your children.
- Please do not tell us that you know how we feel unless you also have had a child die.
- Please don't ask if we are feeling better now. We may say, "Yes, we are fine", but inside there is a hole that will never go away.
- Please do not tell us we were lucky to have had them for so many years. It would be like us asking you which year you would pick for your child to die.
- Please, do not think you have to fix our pain, because we know you can't. No one can take the pain we feel away.
- Please let us talk about our child. Let us tell you we miss our children. We need to say that out loud. Saying you are sorry they are gone is all we need to hear.
- Please mention our children when we are around so we know they are remembered.
- The best thing you could do for us is just listen and let us cry. And if we need to laugh because we remember that giggle, that too is part of our healing.



OUR CHILDREN

*Everyone loves a child
 A child who laughs and plays.
 A pretty face, a sparkling smile,
 A child with winning ways.
 But, is our love confined to those
 Who are perfect, well and strong?
 Does it include all boys and girls
 Who in another class belong?
 A crippled arm or twisted leg -
 Of course, that matters not.
 These children are still held so dear,
 We cherish them a lot.
 But then sometimes we see a child
 Who has a crippled mind
 Out of the shadows he looks on
 Love and trust to find.
 He may be cast aside by some
 Forgotten, hidden, lost!
 This special child whose lonely path
 A great affliction crossed.
 He needs our wisdom and our strength.
 He needs our help and care.
 To God all children are the same
 And they are ours to share.
 So let us lend a special note
 Of warmth for children who
 Will never reach the mental age
 That other children do.*

- Edna Massimilla

For support in your area contact:

THE COMPASSIONATE FRIENDS OF CANADA



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A Child With Special Needs Has Died



THE COMPASSIONATE FRIENDS OF CANADA

An international peer support
organization for bereaved parents and
their surviving children

In the Beginning

The birth of a child with a disability, or the discovery that a child has a lifetime of special needs, is traumatic, and has profound effects on the family. As a parent, you experience the heartbreak of coming to terms with a reality that, at times, may seem to offer very little hope: the challenge of limited physical and mental abilities; a lifetime of artificial means for survival; a healthy mind trapped inside a non-functional body. You may have found yourself grieving both for yourself and for the imagined child that was to be.

Your child's diagnosed disabilities may have created feelings of shock, denial, anger, fear, guilt, disappointment, confusion, frustration, and powerlessness. In addition, intimidation, isolation, and rejection by family and/or friends may have added to your grief.

The challenge of raising a child with special needs may involve researching and collecting information, finding support groups, devising nutritional feeding supports, physical therapy programs, special education, special transportation, overwhelming financial concerns, stress, family counselling, legal aspects, improvising, working with the system, special equipment, endless appointments with doctors and therapists, the constant juggling of medications and, sometimes, more often than not, hospitalization.

The Journey

No parent wants his or her child to be sick, disabled, or harmed in any way. It is not an experience anyone expects to have; rather, it is a journey that is unplanned. The terrain

families must travel is often rough in places. Lifestyle changes, communication and adjustments to family roles become crucial. Some family units may even disintegrate because one of the parents could not cope. And yet, the majority of families are able to find the strength within themselves and among their circles of support to adapt to and handle the stress and challenges that may accompany their child's illness or disability.

A Special Relationship

A Special Needs child initially may be a source of grief, then a source of wonder and of a special relationship. A strong bond develops between parents who care for and learn from their special child. Despite the struggle there is a joy in watching one's child triumph over life's daily challenges.

Some children, unable to communicate verbally, talk volumes through their eyes, their touch, their smile and through sounds and actions uniquely theirs. They become the teachers, showing those around them the power of courage and unconditional love. Feelings of personal growth are often, in retrospect, astounding to many parents, in fact a blessing!

When A Death Occurs

Then, when death occurs, the old grief is awakened, bringing with it a chaos of feelings, thoughts and a unique loneliness. In many cases the child and parent have gone through months, or more likely even years, of fighting the odds, becoming a team, and developing a unique relationship. But death severed that physical relationship and created an abyss of despair like no other. This person was a loved child, first and foremost. Their development may have been

different from that of other children, but this did not make them less valuable, less human, less important, or in less need of love and parenting. The child came first, a blessing to love and enjoy; their disability came second.

Do's and Don'ts

- Please don't assume that our family and all involved are better off. I would grieve the same had this been a "normal" child.
- Please know that I did not see disabled. I saw a child who had enormous potential. All I had to do was find a way to help them express themselves.
- Please do not try to make a parent who is suffering the death of their child do things that they are not ready to do in an attempt to help them. They will do them when they are ready.
- Please do not stop talking about our child because you think it will hurt us. It hurts us more when you are silent. The silence is what hurts; we need to hear their name...please say their name.
- Please don't tell us that they are in a better place. They are not here with us. Don't tell us that our children were unhappy because they had a disability. They smiled just like your children and were upset and angry just like your children. Please don't tell us that at least they are not suffering because we, as parents who loved them, do not understand why they had to suffer at all.