



*A support group for parents,
grandparents and siblings who have suffered the
death of a child, grandchild or sibling.*

PROLONGED ILLNESS

While there are universal similarities in parental grief there are some aspects that are unique to the circumstances of the child's death. There is no "one size fits all" resolution of the grief parents experience upon the death of a child. Many facets of a parent's grief after a child dies from a prolonged illness are quite similar to the grief experienced by any parent when a precious child dies. It has been said that "every death is a sudden death". Although parents may have been told that their child could die and may have watched the child getting weaker and weaker, no parent really wants to believe that his or her child will die. We always hope that ours will be the exception. Ours will be the one that has a miraculous cure. Such is the power of hope... and the power of denial. When our child dies after lengthy suffering with an incurable disease or illness, some people, even some other bereaved parents, think that we are better prepared for death; that the shock is not as great. WRONG! We may have had time to talk with the child about death, and time to "say goodbye" but his or her death still renders a terrible blow. In her early work on Death and Dying, Elizabeth Kubler Ross described the experience of the dying, and her words sometimes seem to explain our feelings as well. The stages she described are similar to the process we go through when we face the idea that our child is suffering from, and ultimately dying of, a disease or illness. Although parents whose children die suddenly will feel these same emotions, the parent of a child with a terminal illness often experiences them on two levels - first during the child's illness and again after his/her death.

THE STAGES:

DENIAL: Certainly we deny, vehemently. Not our child! This child will be the exception — a miracle will happen. Then, after the death, it is not uncommon to feel that we did not “do enough” or act soon enough. We suffer with the “what ifs”. What if we had tried another doctor, another medicine, prayed harder, etc - could it have made a difference? Or perhaps we wonder if we did too much. We ask ourselves if we should have agreed to so many painful tests and futile procedures.

BARGAINING: How many times, watching our child suffer, have we asked that we be allowed to do the suffering for him or her? How eagerly we wish to take his or her place in order that he/she might live a long and full life.

ANGER: Often the anger that parents feel is openly expressed, especially when we watch our child endure painful tests and procedures. We are angry at the situation, at the medical staff, at God, and often at our own inability to “fix” things. Sometimes our anger manifests itself with loud words and gestures, sometimes with tears. Anger and guilt are often seen as very closely related. Much of the anger parents feel may be because of their own feelings of guilt. It is not uncommon for parents of a sick child to blame themselves for the illness. It may have been in the family and was inherited from us. The mystery of genetics often unfolds with startling clarity after the fact. Our brain knows that we are not at fault, but our heart is not listening to our brain. Perhaps the parents have been presented with choices regarding the child’s treatment, and later we wonder - did we make the right decision? It is important to remember that the choices you made were made with love and with the best advice available to you.

DEPRESSION: Parents try to keep their spirits up for the sake of the ill child, or for their other children. It is hard, but we become good actors - pasting on a smile while our hearts are breaking. Often parents are able to “hold it together ” during the illness. After the death we finally allow ourselves to succumb to the emotions we have been repressing for some time. Sometimes parents are not so much depressed as they are emotionally (and physically) exhausted. It is also worth noting that depression is quite normal during grief.

ACCEPTANCE: Although we may come to accept the situation and the illness, for many of us the death, when it happens, is still unacceptable. In the back of our minds we did not want to believe it would really happen; and now we don’t want to believe that our child has died. People try to console us by saying that the child is at peace now and is no longer suffering. We know this fact and it does help some; but it does little to ease our hurt and pain. In fact we may feel guilty if we experience sensations of relief that we no longer must watch our child’s suffering, or that we no longer need to spend endless days and nights at the hospital, leaving family and friends to care for our other children. Of course

we are relieved, but that does not mean that we miss our child any less, or that we do not yearn to hold him/her one more time. Be patient with yourself as you work through the process and resolve these issues in your own grief. Parents often find that talking with others who have had similar experiences is very helpful. Consider a support group, like the Bereaved Parents of the USA, where you will meet others who are also mourning the death of a beloved child and who are willing to listen and to share.

For Further Information Contact
BEREAVED PARENTS OF THE USA

P.O. Box 95
Park Forest, IL 60466
Phone and Fax: 708/748-7866
Web Site: www.bereavedparentsusa.org

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