

Support for Bereaved Parents

The death of a child is undoubtedly one of the most difficult and devastating experiences a parent can imagine. Most parents mark their lives as before the death and after the death. The life they knew, the family they were, is forever changed. Regardless of the age of the child or the circumstances of the death, it is almost impossible to comprehend how this may change a family's life forever.

While there are some common reactions to the death of a child, every individual is unique and will cope with the death in their own way and in their own time. No one will grieve in exactly the same way. Their experience will be influenced by a variety of factors:

- The age and the relationship to the child who has died
- The circumstances surrounding the death
- The support system available to them
- Their cultural and religious background
- Prior loss history
- Their unique coping style

Coping with Grief

The idea of a timeline, stages or phases, can help normalize some of the experiences of grieving parents but it also oversimplifies them. Too often it gives parents unrealistic expectations, and even more challenging, expectations from others of how they should be feeling and behaving. It also presents a false pretense that you can “get over it.” These phases are not fixed or sequential. Grief is more likely to come in waves, sometimes unpredictable, and rarely in a predictable order. A series of good days may be followed by a bad day or vice versa. Often referred to as “grief attacks,” they can be frightening and leave a parent feeling overwhelmed. Suddenly a song on the radio, a TV commercial or a scent triggers a memory of the child, and all the feelings and emotions come racing back in an instant. This is a natural response to grief, but with time the intensity and the frequency of this level of grief typically do decrease.

A parent grieves forever when a child dies. Death does not sever the bond between child and parent; they remain connected throughout life regardless of death. But the emotions and pain associated with grief may also continue throughout life. Most parents will find the emotions gradually have less intensity and do come with less frequency as time passes, but the love of a child remains.

Grief is physical, emotional, cognitive, spiritual, and social experience following the death of a loved one. Some of the more common feelings and behaviors parents may experience following their child's death include:



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- **Shock, Numbness, Disbelief** – Immediately following their child’s death, many parents describe feeling an overwhelming numbness or daze, as being in a fog. Such feelings may temporarily protect parents from the full reality during the immediate moments after the death. Feelings of numbness and disbelief help to insulate parents from the reality of the death until they are more able to tolerate such an unimaginable loss. Many parents focus on taking care of others during this time, along with the necessary tasks of making funeral and burial arrangements. Some parents describe being in a dream-like state, believing they will wake up and find that none of this is true.

The danger becomes when parents receive comments such as, “they look so good” or are “doing so well”. Parents begin to feel the responsibility to meet these expectations and often feel they have failed when they begin to feel the full impact of the death, feeling embarrassed, and wanting to protect others from their feelings when they truly crash and begin to feel the full impact of the death.

- **Sadness, Depression**- Nothing in life prepares a parent for the pain of losing a child. Crying is a part of healing. There will be sadness, debilitating at times, that stops some parents from getting out of bed or from taking two steps out their door. Other times, grief may be an emptiness that nobody else can fill. Bereaved parents sometimes describe everything as gray. Again, the intensity and frequency of this sadness will decrease with time, but most bereaved parents report some level of sadness is with them always.

On-going assessment and support is crucial throughout the grief journey to understand the unique needs of each parent following the death of their child. With a normal progression of grief work, the intensity of sadness will change as parents feel some periods of relief. But if a clinical depression is present, feelings of intense sadness tend to be more pervasive, with the person rarely getting any relief from their symptoms. For parents experiencing a clinical depression, additional support will be needed. Of note, it is normal for parents to express the wish to die so they can be with their child. However, parents who state they’ve made a plan for how their death will occur need immediate intervention. Special consideration and response by referral to mental health professionals may be necessary for parents and/or family members who have a prior psychiatric history.

- **Anger**-Parents have the right to feel angry after the death of their child. It is against the natural order of life; it is unfair that their child wasn’t allowed to grow up. They may have also witnessed their child suffering, which can intensify their feelings of helplessness, and add to their anger. However, the intensity of their anger may vary based on their



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individual coping styles. Some people are more comfortable expressing anger than sadness. The level of anger may also be influenced by cause of death. There may be anger directed to others: doctors, spouses, and others perceived as being responsible. Additionally, it may be directed at themselves for not preventing the death. Parents often need to find blame in order to try to make sense of it. Parents may also be angry with God or begin questioning their faith, but mostly the anger is simply because their child is not there to hug and hold ever again. They may even be angry at their child, in particular, if in some way their child's behavior contributed to their death. Were they compliant with their medications? Why didn't he look both ways before crossing the street? Just angry that they died.

To be angry is natural and even often necessary. The concern is when a bereaved parent's anger hurts others or is unsafely expressed. Others often try to contain or neutralize a person's anger, or may offer quick fixes or try to explain away the death as they are uncomfortable with the intensity of these feelings. At times such as these, it is far more important to validate a parent's feelings thereby helping them to safely express their anger, for it often needs to be expressed before it can be resolved.

- **Guilt**-No matter the reason for the death, parents will blame themselves. Every parent will question what they could or should have done differently. They will rethink and question every decision and event that lead up to the death. Parents will naturally explore the "what if" questions regardless of cause of death.

The death of a child challenges the core belief that it is a parent's job to protect their child. Parents feel a sense of failure. Guilt is also a part of a larger attempt to feel some control, to lay blame, to attribute cause, to make sense of the death. It is important to allow a parent to question "if only..." and to process decisions made for the child's care. It may take time for parents to arrive at a belief they really did make the best decisions for their child with the information that they had at that time.

Some parents may feel guilty when they feel a level of relief after their child has died. This relief may be connected to the fact that their child is no longer suffering. It may be relief from the constant stress of caring for their child's complex medical needs. Eventually the parents may feel guilt over beginning to enjoy new found time after days, weeks, or years of caring for their child.

- **Anxiety, Panic, Fear**- A parent's sense of security is forever changed. There can be overwhelming feelings of panic in response to their lack of control. The world does not feel safe anymore. Nothing feels predictable or controllable, which may cause parents to fear for the safety of others, or fear that bad things may happen again.

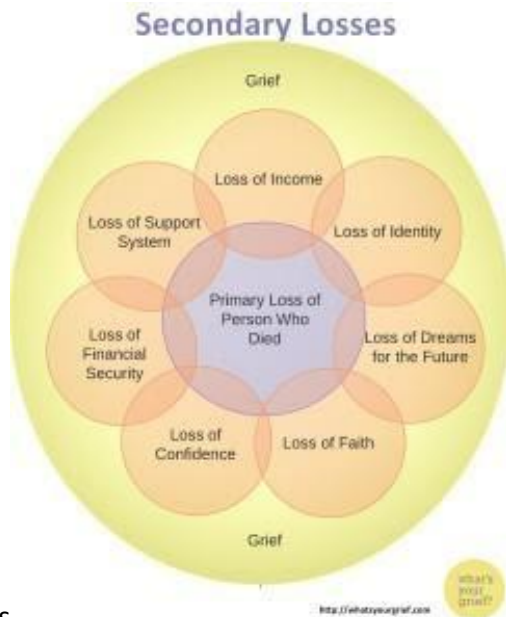


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- **Disorganization, Confusion-** Parents report not being able to complete a task, being forgetful, distracted, or generally experiencing a state of mind that may be described as going crazy syndrome. Many parents also struggle with short-term memory impairment, along with the inability to concentrate. They may have difficulty making decisions or simply performing everyday tasks, such as going to the store and remembering what they came to buy, or finding themselves lost on the way home.
- **Longing, Yearning-** A parent's longing for their deceased child can be equally excruciating. Some describe it as a permanent physical ache that does not go away. Others describe it as feeling that a part of their body has been amputated leaving them to survive without the assistance of a complete and fully functioning body. Parents talk about missing the smell, touch, sight, and sound of their child, and have a yearning just to feel their child's presence again. Many look for clues, taking such signs to mean their child is sending a message that he/she is okay.
- **Dreams** - Many parents report having dreams about their child and/or having a sense of their child being "present" These dreams can be very powerful for a parent as they often fulfill a deep longing to know that their child is alive and well in a different realm. This can vary depending on the families' beliefs and faith, but most report comfort when they have these dream experiences. Some parent long for their child to "appear to them" in a dream and can feel angry and jealous if another family member has reported dreaming of the child and they have not. Some parents, though, fear having a dream as afraid it will feel too real.
- **Somatic symptoms-** Grief impacts on a physical level as well, as parents will grieve with their bodies. Physical reactions may include: difficulty eating or over-eating, inability to sleep or sleeping all the time, upset stomach, physical exhaustion, restlessness, irritability, headache, heart palpitations, nervousness or shortness of breath. Preexisting physical ailments may become more aggravated by grief. This is normal, but if these reactions persist or interfere with daily functioning and responsibilities, parents should be encouraged to seek assistance from a doctor or a counselor.



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Secondary Losses

Often unrecognized or minimized are the secondary losses. Many parents report a loss of identity after the death of their child. After years of caregiving, there can be a question of who am I now? What do I have to offer others? Many parents also report feeling the loss of the medical team. After years and years of appointments, hospitalizations, the medical team is often described as “part of the family”. But now there are no more appointments. No more visits to the hospital. Support system may also change. Some friends and family may have been able to step in during the crisis but can not tolerate the ongoing pain or bear witness to the parent’s grief. Relationships change. “It is sad and frustrating, but very true that our address book changes. Some people feel as if our loss is contagious. Or maybe they feel that we aren’t progressing fast enough or that we are maudlin and not upbeat enough. We often feel abandoned by those we felt should have been there to count on, creating a new grief of the loss of those relationships.” Lynn Follett, Stepping Stones Bereavement Services. Many parents also talk about the loss of the child’s peer group and missing the energy that the friends brought to the home. Or the challenge of watching the first day of school as the friends continue to grow up and reach other milestones. XXXXXXXX



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