



Grief for People with Down Syndrome and their Families

Why is grief so important and how is it different for People with Down Syndrome?

- First, grief is exceptionally important, both for our family members with Down syndrome and for ourselves. Many authors have written convincingly on the importance of grief in our lives. Psychologist Francis Weller writes that “In truth, without some familiarity with sorrow, we do not mature as men and women. It is the broken heart, the heart that knows sorrow that is also capable of genuine love”. African advocate Sobonfu Somé taught that grief and loss are our constant companions, *whether or not we understand and accept them*. Similarly, the Irish author Kevin Toolis found that despite experiencing a traditional wake for his father (on Achill Island) that *grief is a process that is often diminished or passed over in our cultures*. Too often we are told to “get over it,” or “get on with our lives.” Even though, as these and other authors have found, grief in community is a balm for the soul.
- People with Down syndrome, if given the opportunity, will welcome and embrace grief wholeheartedly, even encouraging others in the family to open their hearts to the process.

But its Important to understand how People with Down syndrome experience grief.

- We found that they often grieve differently because they have a photographic-like visual memory. This allows them to recall events from the past as-if-happening all over again {with all the original feelings and emotions intact}. This can include good experiences, (such as a birthday celebration), but it may also include painful experiences such as the loss of a loved one.

- What sets this type kind of memory off is some type of reminder of the original event. (Such as a picture or mention of a loss loved one).
- If strong emotions occur, this can be very alarming to family members who are taken aback by the intensity of the feelings.
- They may fear that the person with Down syndrome may be stuck or overwhelmed by the emotion.
- But....In most instances this is often ... ***“in the moment”*** and not long lasting.
- This “in the moment” experience of loss- may be true even if there is a recent loss.
- In these instances, familiar others can often tell when there is a shift out of the emotional state, allowing them then to divert the person with Down syndrome to something else.
- If however, the grief is continuous: It may be helpful to look for triggers (what sets it off)

We will discuss all the possible ways families can help members with Down syndrome when this form of grief occurs