Grief
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I’ve heard it said that everyone experiences loss in their lives, although some people have more than others. People with Down syndrome encounter situations involving grief and loss just like anyone else. They may lose grandparents or friends who have health problems. As our population lives to an older age, many of them experience the loss of parents or siblings. Our patients have the added challenge of living in residential programs or attending day programs where staff turnover may be high, especially in light of current budget issues in Illinois. Oftentimes, the loss of favorite staff who were a regular part of their lives can be very significant. It can be difficult to know how to help someone with Down syndrome work through feelings of grief and loss. Here are ten things I know:

1. **People with Down syndrome and other intellectual disabilities experience grief just like anyone else.**
   Some people have a misconception that people with Down syndrome don’t have feelings about a significant loss because they don’t understand what happened. This is not true. People with Down syndrome and other intellectual disabilities experience feelings of sadness, anger, and shock over the loss of an important person just like people in the typical population.

2. **People with Down syndrome need to be told the truth about the death or terminal illness of someone important to them in a way they can understand it.**
   Well-meaning family members may feel that it is better not to tell the person with Down syndrome that someone is terminally ill or that they have died. They don’t want that person to be upset. However, just because someone has an intellectual disability or limited verbal communication skills doesn’t mean they don’t know something is wrong. Pretending that nothing has happened is even more confusing than acknowledging it. It is important to try to explain what is going on, even if it’s a very simple explanation like “Dad is sick” or “Dad died. He’s in heaven.” Interestingly, people with Down syndrome often seem to know about heaven and have some kind of sense that there is an afterlife. Some people even point at the sky and say the person’s name or even talk about seeing or talking to a person who’s died.

3. **People with Down syndrome and other intellectual disabilities may be excluded from the rituals that usually occur around death.**
   Family members may feel that the person would be “too upset” or it would be “too confusing” if they attended the funeral or other family events associated with the death. However, this can sometimes be even more confusing. The person with Down syndrome may have last seen the person who died when they were alive in the hospital, for instance, and think that the person is still in the hospital. It’s important to include the person in some part of the family ritual around death. There are situations where it may be too difficult for someone to attend a funeral or where it is not possible due to geographic restrictions but it’s still possible to involve the person with Down syndrome in some part of the family ritual or for the family to have its own memorial service or ritual with that person.
4. **People with Down syndrome may express their grief in ways that are different from the general population.**
   Even in the general population, everyone expresses grief differently. People with Down syndrome can also have different reactions to grief than their caregivers expect. They may not seem to have a reaction to the loss at the time but may seem withdrawn and depressed months later. They may talk about the person but seem confused about where they are. They may be angry and irritable and lash out at peers or staff. These are all normal parts of the grief process, which includes sadness and anger. People with Down syndrome may also blame themselves for the death. They need reassurance that it is not their fault.

5. **People with Down syndrome may have a delayed reaction to grief and loss.**
   It may take more time for the person with Down syndrome to process the loss. Sometimes people do not seem to have any emotional reaction for months or even a couple of years. They then seem to be going through a grief process, talking about and expressing sad feelings about the loss. This is not unusual. It can be difficult for families and caregivers, as the person may be exhibiting a typical grief reaction when other family members are starting to move forward after the loss.

6. **People with Down syndrome may grieve for longer periods of time than those in the general population.**
   People with Down syndrome remember things very well and can “relive” memories with a lost person even many years later. This can make their grief last longer and be more complicated. They may talk about memories they have with the person who died as if they just happened and vividly remember the details. This can be difficult for other family members or caregivers who feel that the person “should be over it” by now or shouldn’t be thinking about it so much.

7. **People with Down syndrome may have had multiple experiences that have caused grief and loss.**
   In addition to the deaths of friends and family members, people with Down syndrome often experience the loss of staff they are close to who move on to other jobs. People with Down syndrome can also become very attached to attending their school or day program and have a difficult time when they age out of school or change programs. The loss of their familiar friends and staff as well as the routine and identity of being a student or participant in that program can be very significant to them. They may have moved from one home to another at their residential program or even have moved to a different residential program. It can be difficult for anyone to cope with multiple losses in a short period of time. It is important to think through all the losses the person has experienced when considering how to best support them.

8. **All people need opportunities to grieve, even if they are not able to express themselves verbally.**
   Just because someone can’t express something verbally does not mean that they do not need opportunities to acknowledge and grieve a loss. Sometimes all it takes to acknowledge grief is
spending time with the person looking through pictures of happy times with someone who has
died or acknowledging their feelings by saying “you are sad” and showing them that you are
there to support them.

9. **A person with Down syndrome may have a more dependent relationship with their parents than their siblings. This can affect what the loss means to them.**

   In addition to mourning the loss of the parent, the person with Down syndrome may be
   wondering who is going to care for them, help them with basic tasks, or make sure that they get
to places they need to go. People with Down syndrome often have fewer people in their circles
   of social support and the loss of a parent may be more significant to them than it is to other
   members of the family.

10. **It’s okay to ask for help.**

    The person with Down syndrome may need more help processing the loss than family or
caregivers can provide. The family may also need professional help to find the best way to
support the person with Down syndrome and care for themselves during a difficult time.