

**Helping Families of Children with Williams Syndrome  
Cope with the Death of a Loved One; Getting started...**  
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Helping a typically developing child cope with the loss of a loved one poses enormous challenges. Helping a child with Williams Syndrome to cope with loss, and learning, as parents, how to deal with the complexities of WS in order to help both our children and ourselves can be especially difficult - for families, therapists, and teachers. Some of the questions that come to mind concern:

What should adults tell a child? When there is a death the adults may want to protect the child with WS from painful feelings and facts, and may worry that talking about it will make it harder.

What to tell younger children or children with significant communication difficulty who may not be able to ask the questions that guide conversations - adults have to do the 'work' of figuring out what they are feeling or thinking.

How to determine what a child's experience of the loss is when the child may express their feelings in unique ways?

Who should talk about the person who died, and who should help the child with his feelings; when and how?

What if the child becomes too upset and can't calm down?

What if the child becomes overly focused on the loss?

**How do children with Williams syndrome express grief**

In general children with Williams syndrome experience grief individually and in varied ways just as in children without WS. Children who experience a significant loss...

- may become more anxious about mild illnesses in others (e.g. mother has a slight cold may be cause for great worry)
- may become more anxious about mild or significant health issues they have
- may worry more loss of other key people
- may have new difficulties with separation for school or at night,
- may become more irritable or more easily tearful
- may have more difficulty concentrating
- may have more sleep difficulties

- may perseverate on the event – wanting to hear repeatedly what happened, how the person died, what happens after you die, and posing other questions to try to gain some understanding of what is so incomprehensible for all of us
- may worry a great deal about how other family members will cope

Sometimes children, with or without WS, do *not* show outward signs of grief initially or sometimes even over time. This can be for several reasons:

Sometimes children notice that talking about the loss makes adults sad. Knowing this, they may avoid talking about it, even though it could be helpful for them to engage in simple discussions.

Sometimes children find it too painful to think about the loss and cope at first by thinking about / doing other things. This can feel to others as if the child doesn't care but is usually just the child's emotional system trying to cope with pain.

Sometimes children experience and express intense sadness one minute and seem fine or even quite happy the next. This shifting in emotional states is common in children and adults too who are experiencing grief. This shift in emotions can be more intense with children with WS, who often seem in general, to experience their emotions more intensely and seem to be able to shift emotions more quickly. This ability to shift emotions can provide a helpful protective 'buffer' for children as they grieve. It is as if the soul 'needs a break' from sadness to regain well-being before experiencing the next round of sadness.

Sometimes children with WS, like typically developing children, can become 'stuck' on feeling sad or on wanting to hear the details of the death many times over. If caretakers are finding that the child is having trouble feeling OK again, it can help to do some fun high energy activities (put on some upbeat music and have a dance party) to take some 'grief breaks' as well as have times when they all talk about it. This external structure can help the child manage potentially overwhelming internal feelings.

Usually over time children who don't initially show signs of grief will begin expressing this in any number of direct or indirect ways.

#### **General Recommendations for families:**

Talk to your child with Williams syndrome (and your other children) about what happened, how the person died, what it means to die if this is new for the child. If the child doesn't seem to want to do this at first, try again at a different time. Gear your conversation to their level of understanding and be consistent with your own belief system. Tell the child in a way they can process, what happened. Concrete specific information can feel 'too sad' to adults sometimes,

but usually for children, some specific knowledge of just what happened, in general lowers anxiety as it adds some 'logic' to what for most of us seems so illogical.

If the person who died happens to be an individual with Williams syndrome, it can be very important to let your child know that these occurrences are rare in such a way they can believe in that knowledge and get past their natural anxieties, and it's important for you to trust in that knowledge as well. Social media has developed world-wide connections where once there were none, and is also a bit of an "echo chamber". Messages, both good and bad, are posted and shared repeatedly, magnifying our perception of their true occurrence. It's critical that we all remember that the incidence of tragic outcomes in WS has not changed. They are still quite rare. Understanding this ourselves, will help to allay our own anxieties as well as those of our children. Consider the following ideas as well:

- Share happy memories of the individual with your child - with pictures, videos etc.
- It's OK to cry with your child.
- If you find it's too painful to have these conversations with your child see if anyone else can partner with you – a family friend or relative or a special favorite babysitter, or school or private therapist.
- If the child isn't about the individual and it's someone who had a key role in the child's life, caretakers can help by talking about the person, through references of every day memories ("Oh Grandma used to love when you sang that song" etc.). This lets the child know it's OK to talk about the person who died, and helps them experience these happy memories with you, naturally, over time, without a sense of overwhelming sadness.

### **Ways of saying goodbye**

While it is a very individual decision whether to have children participate in funeral events, having the child participate in some kind of event or several events that help them say goodbye to the person, help them feel part of celebrating the person's life, is usually very beneficial in the grieving process. Some ceremonial activities families can do with children:

Plant a 'tree of remembering' for the person who died.

Set off balloons to say goodbye (there are many ways people choose to participate in this tradition; some people are concerned about potential environmental impact of this activity, while others are not)

Make cards/pictures/videos for others' effected by the loss (e.g. if a grandmother has died make something for grandfather)

Make a memory book of happy times with the person

Go to a place several times where the person and the child did special things (e.g. a park or the zoo or library etc.) and share memories or just enjoy the outing knowing the memories are there

For some families and children, visiting a grave site once or often and talking to the person who died or talking about them or leaving special memory objects can be healing. Visiting on 'anniversary' dates, which in the beginning might be a week, month, 6 months or a year, or after the person has died, or the person's birthday, etc. can be helpful.

### **A Team Approach to Dealing with Loss**

While many children with Williams syndrome have access to therapists at school, the issues surrounding grief don't typically fall within the training or expertise of these therapists. Some children have a school counselor or social worker they can speak to, but this isn't the norm, and even they, aren't always well prepared to help with grief. Parents readily turn to a speech-language therapist for communication questions; a behavior specialist for behavioral concerns; a teacher for learning or social concerns; an occupational therapist for sensory issues, etc. In what specialist's domain, however, is helping the child to cope with grief and loss?

It is ironic in our culture that we have come so far in understanding the need for such practices as preparing, explaining, previewing, writing Social Stories™, role playing, and coming together as a support team for children with WS, around so many big and small issues. Yet, for something as momentous as the death of a loved one, we often find ourselves at a loss for what to do. Often—perhaps out of fear of “doing the wrong thing” or a feeling of wanting to protect the child—we do nothing at all.

There are some excellent resources available (see the list at the end of this article) specifically for children; however, many in the field of education and/or special education are not familiar with them. Hence, parents often feel that they don't know what to do, or whom to seek out for help. Likewise, teachers and therapists often feel that because the subject matter is beyond their areas of expertise, they are reluctant to approach the topic of loss. The result is that many children with WS who experience a tragic loss are neither provided with explanations or ways to make sense of their loss and new reality; nor do they receive the ongoing support they need to understand and cope with complicated, intense, and evolving emotions.

Helping a child cope with loss and grief is a process that must be steered by the family. However, it can also be part of the role of all of those who have a close relationship with the child and family. Just as a child's parents and school personnel come together as a team to help the child cope with other difficult emotional challenges, parents, family and professionals can join together to help a child cope with loss. That said, initiating this process—the “getting-started” piece can seem insurmountable.

### **A Simple *Start-Up Guide* for Family, Friends, Teachers, and Therapists:**

1. The first, most important step is to make sure that parents and immediate family members most impacted by the loss have the support they need, and if not, to help them access it. What each family finds supportive is highly individual, ranging from mental health therapists and/or support groups to religious groups and/or family, friends, or other natural supports. It is important to bear in mind that parents need to feel sufficiently supported emotionally in order to best help their children to cope with loss.
2. We recommend talking openly with families about what sort of help they may want. Since, in all likelihood, most families have not faced this situation before, and would also be in a state of intense grieving themselves, if the loss is of a close family member, offering “menu options” of ways to help the child can make the process easier. For instance, ask the parent(s) if he or she would like to provide pictures so that teachers or therapists can create a “memory book” for the child. Provide sample Social Stories™ from which the family could select the one that best fits their needs. Ask the parent(s) if it would make it easier for the family to have one of the child's therapists or his or her special education teacher available for some early conversations. This can be especially helpful for parents who really want to talk with their child about the loss but are afraid that they will become too distraught to do so.
3. There are many excellent children's books about loss and grief for typically developing children. The child's family and friends can review these to determine which of them might be useful, given the child's level of communication and understanding, and the family's beliefs.
4. A grief or other mental health specialist, if available, can provide consultation to, or direct work with the child, his or her team, and/or family.

### **Special considerations and circumstances for children with WS:**

While for the most part the grieving process for children with Williams syndrome is like that of other children (naturally including great variation), there are some special considerations as well:

1. Children with WS, as mentioned above, seem to feel and express their emotions more intensely, for both happy emotions as well as fearful and sad emotions. Clearly having times of intense sadness following a loss is natural and healthy. However, when a child is feeling sad about a loss, this may trigger memories of other losses, other things they are sad about, and the child may need special help in 'turning it around' to move out of an intensely sad mood. We once facilitated a group of young adults with WS who had tragically lost a beloved friend with WS they knew from camps and other gatherings. Each person who wanted to, and most did, shared some memories, and their feelings which often naturally included very sad feelings, and then we practiced "turning it around". A gesture was made of a dial turning one's emotions from sad to happy, ending each person's turn with a happy memory. Remarkably most were able to do this "turning around" process and regain control over their emotions. Many tears were shed, and sadness was shared. But there were also many, many happy memories and most of the young adults experienced being able to be sad but not be rendered overwhelmed with sadness.

2. As mentioned previously, in the very sad situation of when a person with WS dies, there is a special impact for others with WS as well as for their families - even if they did not know the person or did not know them well. Many people with WS feel a special kinship or connection with others with WS, just as many parents feel this towards other children with WS and their families. There is also the very real concern for children with WS about whether the death was related to medical problems associated with WS and if this puts them at more risk. In addition to the knowledge that these outcomes are rare, it can help for particularly anxious older children and young adults to have a "well visit" with their pediatrician or doctor to be reassured about their own health and well-being.

3. Some children, especially younger children with WS who are just learning the social rules and norms overall, may have difficulty at first figuring out when/with whom one talks about the loss. This is often the case for young children in general, but can be exacerbated in children with WS for whom getting a warm emotional response from others can be especially high on their priority list. A child may find, for instance that telling someone at the grocery store about their loss evokes a very warm reaction and they may then bring the subject up again with other relative strangers, seeking another warm reaction. Teaching simple rules of when/where/with whom to talk about this subject is part of teaching children these sorts of social rules in general.

When children don't seem to be able to cope, or adults are having great difficulty helping them navigate this difficult situation, (e.g. the child continues to have difficulties sleeping, eating, feeling times of happiness, for a longer period; or caretakers are finding it very difficult to talk to the child about the loss) seeking professional mental health support from a Social Worker, Psychologist or Psychiatrist who specializes in grief counseling can be very helpful.

With adult support, children are remarkably resilient, and while loss of a loved one changes all of us and is very painful, children, like adults, generally do regain a sense of well being over time.

**Resources:**

**I Miss You: A First Look at Death (First Look at Books) by Pat Thomas, Barron's Educational Series; 1 edition (January 1, 2001)**

*A helpful book for young children explaining death and loss in gentle, matter-of-fact terms.*

**The Invisible String**

by Patrice Karst Devorss & Co.; 14th Printing edition (September 1, 2000)

*A wonderful children's book, a little more complicated, but lovely, about the "invisible string" of love that connects loved ones across distances and life and death.*

**Tear Soup: A Recipe for Healing After Loss Hardcover**

by Pat Schwiebert Grief Watch; 5th edition (June 1, 2005) Grief Watch; 5th edition

*A "story format" book for older elementary or middle school children about the process of grief over time.*

Death and Grieving by Nancy Grace online

<http://www.pathfindersforautism.org/articles/view/parent-tips-death-and-grieving>.

*A helpful, matter-of-fact list of ways to help children with ASD that are quite universal for typically developing children or children with other special needs.*