



EMOTIONAL RESPONSES TO THE DIAGNOSIS OF MPS AND RELATED DISEASES

The diagnosis of MPS and related diseases results in a range of responses in the family of the affected child. While these responses are varied, there are factors which are common to many families. The information in this fact sheet is an overview of the reactions parents may experience. Initial responses may include relief, especially if the parent has sensed that all is not well and searched from doctor to doctor for an answer. While no one wishes for a diagnosis of MPS or related disease, a diagnosis may help to alleviate anxiety, frustration and fear with something concrete. Information can be powerful, and often finding a cause for a child's medical concerns can provide assistance with medical management, treatment, and other appropriate services.

At the time of diagnosis, most parents experience an overwhelming sense of devastation and then progress through the stages of grief. Psychologist Ken Moses has developed theories on the grieving process experienced by parents of children with disabilities. Among the most intense feeling parents of children with special needs experience is grief over the loss of their dreamed-for child. With the loss comes an intense emotional period that is often misunderstood by the individual and those around him or her. It can be helpful for those experiencing the loss to recognize their feelings and reactions as appropriate, given their situation. The following is a description of the grieving process many parents experience when they learn of their child's special needs, and how one might understand and respond helpfully.

Loss of the Dream

When parents are expecting a child, they naturally have dreams for that child: what the child will be as he/she grows up, who he/she will look like, how he/she will do in school, etc. Many times mothers and fathers will not even discuss their own dreams with their partner, although they may assume that the partner knows.

According to Dr. Moses, an underlying dream held by all of us for our children is that they will have a better life than we had. Dr. Moses says, "The only thing a human being can lose in life is a dream. You don't lose the past, only the future...the dream, fantasy, illusion or projection of the future." When parents grieve, it is the loss of the dream that they are grieving. This process has many pieces, but always starts with the shock of the information presented. It is usually followed by denial that the information is correct.

Denial

Denial is a necessary part of grief and should be looked on as helpful. Many parents do not want to admit they denied that their child has a disability, but in looking back, they can see things they did and said that constituted denial. Dr. Moses refers to denial as buying time to permit the person to find internal strength and external support to deal with what has happened. Denial comes in many forms and can last for a short while to many years. In supporting another parent, the most important thing to remember is that this parent is using his or her coping mechanisms to prepare to deal with the situation, and this process is normal, purposeful, and productive.

Dr. Moses refers to four levels of denial as being the most common:

Parents may deny that the child is impaired. “The doctor must be mistaken” is a common response. Some parents seek a second or third opinion.

Parents may accept the diagnosis, but deny the permanence of the disability.

Parents may accept both the diagnosis and permanence but deny the impact on their lives.

Parents may deny their feelings. “Yes...but there is no point in crying over spilt milk.”

It is important to remember that these are normal, helpful reactions to the situation and should be supported as such.

As families adjust to the news, most begin to actively pursue more specific information about the disability and available resources in the community. This gathering of information helps parents move out of the shock and denial they have been experiencing.

Anxiety

Another stage of grieving is panic or anxiety. When parents realize the changes this child may make in their lives they may panic. “What am I going to do?” or “What about his education and future?” are questions that become important to parents. Anxiety can be useful because it helps mobilize and channel the energy needed to make internal and external changes required by the loss. Parents may feel frustrated or inadequate to deal with the situation, and be afraid of the unknown. Acknowledging the anxiety, and the right to feel anxious, can be helpful to families dealing with this stage of grief.

Anger

Reactions during grieving are sometimes seen as exaggerated compared to how a person might normally react to a situation. If a person tends to become angry in any particular situation, he or she might become very angry during the grieving process. Anger is probably the most common stage a parent can expect. Parents may show anger at the professionals who diagnosed their child, at the biological history, or at God for “giving them a burden to carry.”

Most often, however, the irritability and anger are directed at those closest and safest – family members. Insignificant and minor events suddenly seem important and catastrophic. It is extremely difficult to remain close and supportive during this phase of the grief process. Keep in mind that anger may be fueled by feelings of powerlessness, or not feeling in control of the situation.

Guilt

Guilt is often associated with something we did in our own lives. It makes us think back to everything we perceive as bad that we may have done. There may be a tendency to judge our own worth and us.

Many times guilt takes the form of questions, such as, “why me?” or “what did I do to deserve this?” We questions why things exist as they do, who is controlling our lives, and possibly even our belief systems. Sometimes, the answers to these questions are that some things have no explanation. This is hard sometimes for parents to accept. Families should be allowed to share these feelings without being judged.

Depression

Depression serves a purpose in the stages of grief. We should encourage parents to talk about their depressed feelings and acknowledge their needs to search for other ways of looking at their own expectations of themselves and others. When people are depressed tears come frequently; sometimes

everyday activities have no interest. There may be physical symptoms such as sleeplessness or even illness. Again, it is normal to feel this sadness; only very long-term signs of depression are cause for concern.

Fear

Parents have many fears. An underlying fear may be that because the hurt is so great they will never be able to bond with their child or perhaps not with anyone ever again. Ken Moses writes, “When you permit yourself the risk...permit yourself to have dreams and it doesn’t work, the fear is that the pain will be so great, you’ll never permit yourself to risk hoping, or dreaming, ever again.” The feeling of fear and the sharing of that fear are ways parents can find the inner strength and courage to begin to love the child they have.

Adjustment

In this phase of the grieving process, parents begin to see the ways their child is like other children. “Her eyes are blue, just like her father’s,” or “he likes the same food as my other children.” Emotions become less intense and family members can direct more energy to the tasks and joys of daily living. The family begins to find delight in their child. They start to develop new ways of enjoying with each other.

Recurring Cycles of Grief

Grief is a recurring cycle that parents may travel in and out of at various times in their lives and the life of their child with special needs. Major events or changes such as when a child starts an infant or preschool program; when the child reaches school age, puberty or adulthood; when the child leaves the public school system; and when parents retire are all events that may trigger parent’s grief reactions. Holidays, a child’s birthday, and family gatherings might also make parents revisit the loss of their dreamed-for child again.

It is important to recognize that members of the same family may grieve in very different ways and may travel through the stages of grief differently. Recognizing each family member’s individual coping mechanisms and acknowledging them will help reduce the stress that can build in relationships when learning of the diagnosis of a MPS or related disease.

Emotional reactions to the child with MPS and related disease are intense and frequently confused with resentment and frustration, bringing their own added burden of guilt mixed in with pity, love and pain. MPS and related diseases can involve a broad range of disabilities and perhaps behavioral problems. This, in turn, means many parents live in a state of perpetual exhaustion trying to run the gamut of health professionals, educators and therapists while fighting to preserve some normality for their families and deliver the specialized and constant care required by the child with MPS and related diseases.

Through this period, it is important to have hope. We are available to provide you with information and support. The National MPS Society has educational materials and we can connect you with a family in your region who has a child with the same diagnosis. We recognize that the information and support you receive from other families is critical. The mission of the society is to find a cure for MPS and related diseases, and we have provided over \$4 million in research funding. Treatments are being developed, and better knowledge about the disorders leads to improved medical care and overall quality of life. Remember that you are not alone.