



A FAMILY-CENTERED APPROACH TO COPING WITH MPS AND RELATED DISEASES

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Talk about MPS and related diseases with both your MPS child/children and siblings. MPS parents may have a difficult time deciding how much information to give their affected and unaffected children about the disease. Although there may be a tendency to conceal information from children to avoid introducing unnecessary anxiety, it is often best to be as open and honest as possible. Keep in mind that your child/children with MPS and their siblings can be very perceptive. They will likely know if the parents are not being completely honest with them, and may develop feelings of confusion and mistrust. Age-appropriate information can be delivered in small doses and should be geared toward the children's level of understanding. Parents should make sure their child/children with MPS and siblings know that they are available to answer any questions that may result from these discussions. Answers to questions should be honest and straightforward, yet age-appropriate.

Help your child/children with MPS and siblings deal with their feelings about the disease. MPS parents are faced with the difficult task of helping both their affected and unaffected children deal with the wide array of emotions associated with living with MPS. Providing support by listening and discussing these feelings is essential. Younger children may believe that MPS is a punishment for something they have done. Older children may resist discussing their concerns or feelings in order to protect their parents from becoming upset. It is important to reassure children with MPS and their siblings that they did not cause MPS. They must also know that they can talk to their parents about any concerns or feelings without fear of being judged negatively or causing parents to become overly upset. Remember that children's thoughts and feelings about MPS and its impact may change over time. As such, keeping the lines of communication open should be an ongoing task.

Prepare your child/children with MPS and siblings for medical procedures. Children need to know what to expect in their lives. Although parents may think they are protecting their child/children with MPS by withholding information about procedures that may be painful or uncomfortable, this approach may increase anxiety. It is usually a good idea for parents to take the time to prepare both children with MPS and their siblings for upcoming procedures. They should explain why the procedure is being done, who will be performing the procedure, what equipment will be used, whether or not there will be pain or discomfort, and what type of recovery period to expect. While most pediatric hospitals have staff experienced in helping to prepare children for hospitalization, surgery, and various medical procedures, the responsibility of preparing the siblings often falls on the parents! Siblings may experience anxiety related to parents spending increased time away from home, getting less attention from parents, fear of outcome of the procedure being performed, and missing planned events in their own lives due to parental time and resource constraints. Keeping siblings informed makes them feel important and involved, and can minimize resentment and help facilitate healthy parental and sibling relationships. Keep in mind that the information provided does need to be geared toward the age level of the children, and that the children should be encouraged to ask questions until they understand.

Give your child/children with MPS and siblings some choices. At times, children with MPS and their siblings may feel they have little control over their lives. Therefore, it is important for parents to help foster a greater sense of control. This can be accomplished by offering children choices whenever

possible. When appropriate, children with MPS may enjoy being given the choice as to which arm the IV will go into, what they will eat, or when they will do homework or play. Likewise, siblings may enjoy having a choice over which care-giving tasks they will perform and the timing of these tasks.

Help your child/children with MPS and siblings lead as normal a life as possible. Parents should try as much as possible to treat their child/children with MPS and siblings like any other child. While recognizing that children with MPS do have special needs, it is important that parents encourage them and their siblings to participate in activities that involve other children of the same age. Expectations about the types of activities appropriate for children with MPS should be communicated to siblings and playmates by the parents.

Don't be afraid to discipline your child/children with MPS and siblings. Many parents are reluctant to set the same kind of limits with children with MPS as they do with the unaffected siblings. However, just like any other child, children with MPS need discipline from parents. Structure and consistency introduced by parents helps to foster feelings of safety and security in children, which can be very reassuring. Adequate discipline also helps children learn to control their own behavior. Parents should make sure that discipline is consistent among children with MPS and siblings in the household. This helps to foster healthy sibling relationships. Discipline should also be consistent both from day to day and between parents and caregivers. Recommended discipline techniques include praising appropriate behavior, and using time-out in young children, and restricting privileges in older children for inappropriate behavior.

Give your child/children with MPS and siblings responsibilities. Just as children with MPS and their siblings need discipline, they also need to be given responsibilities. Encouraging responsibility is one way to help a child with MPS lead as normal a life as possible. Parents must use judgment in assigning tasks to children with MPS that can be carried out with success. The requirements for the tasks should be clear and consistent. Parents should also remember to acknowledge and offer praise for tasks that have been done well. Siblings can be empowered to help care for their siblings with MPS and may actually enjoy the act of providing care if the tasks are communicated in a clear and consistent manner, and praise is given when appropriate.

Develop and maintain family routines as much as possible. Children typically prefer daily routines that are predictable and consistent. Although this is not always possible in an MPS family, an effort should be made to maintain regular routines and schedules for all family members.

Be mindful of what your child/children with MPS and siblings can overhear. Parents should be mindful about what is said within earshot of their child/children with MPS and siblings. It is important that children receive consistent and age-appropriate information from their parents. They also should not be exposed to conflicts related to MPS and its management that may take place in the home or medical environment. This can lead to feelings of insecurity and mistrust.

Prepare your child/children with MPS and siblings for the reaction of others. Children with MPS and their siblings often don't know how or what to tell others about the disease. Parents can help their children by suggesting various age-appropriate explanations of what MPS is and how it affects people. The issue of how to handle any teasing should also be discussed with children. Role-playing may be useful in helping children to craft responses to questions or teasing that may come from those unfamiliar with MPS.

This fact sheet is not intended to replace medical advice or care. The contents of and opinions expressed in the fact sheet do not necessarily reflect the views of the National MPS Society or its membership.