

For Parents of Children with Diamond Blackfan Anemia



Parenting Corner Q&A

When your child is evaluated for Diamond Blackfan Anemia (DBA), the process can be stressful and filled with uncertainties and anxiety. Once a diagnosis is made, the initial feelings of relief for having a diagnosis can be replaced with new concerns: What is DBA? What does this mean for my child? The time from initial symptoms to diagnosis can be long, stressful, and disruptive. You, your spouse, and other adults close to your child may react with a range of emotions, such as concern, anger, sadness, and worry.

Learning that your child has DBA affects each member of the family. The siblings of a child who has DBA can also express a range of emotions and reactions. The nature of the relationship and the emotions expressed between siblings can be influenced by a variety of factors:

- Family resources
- Number of children in the family
- Family lifestyle
- Parenting styles
- Personality types of the children
- Age differences between siblings
- Stressors in the family
- Coping patterns that already exist within the family
- Availability of support services

What reactions can siblings have?

A sibling can have many reactions ranging from positive feelings of compassion to more challenging feelings of jealousy and anger. Due to their young age and lack of information about DBA, siblings may be less equipped to understand their reactions. Siblings can be jealous of extra attention and care that parents and other relatives give to the child who has DBA. Jealousy can worsen during times of treatment or hospitalization and can contribute to the well sibling's perception of being less important in the family. These negative feelings can lead to behavior problems.

What behavior should I watch for?

Siblings can demonstrate a variety of emotions and behaviors at home or in school:

- whining
- complaining
- tantrums
- regression (forgetting how to do things they recently learned how to do)
- embarrassment around peers
- concern over parental stress and grief
- concern about taking on a caregiving role
- sense of isolation
- aggressive behavior
- a need to try to make up for shortcomings of a brother or sister

What can I do?

Finding out that your child has DBA can be scary and overwhelming. Start by understanding your own emotions. How you react can influence your children's reaction. Help your children manage their feelings by modeling healthy coping strategies and monitoring your own emotional state. Come to terms with what a diagnosis of DBA might

mean for you and your family. Talk to other DBA families and become as knowledgeable as possible. Next, share as much information as you can. Adults commonly try to protect young siblings by withholding information. Often, this occurs because siblings are considered too young to understand. However, children may overhear parts of conversations about their brother or sister. What a sibling imagines by piecing together things they have heard can be worse than reality. Siblings need information, reassurance, and coping strategies just as parents do. Talking directly with siblings about DBA and treatments can clear up any misunderstandings. Also, encourage children to talk with their affected brother or sister about DBA, how he or she is feeling, and what it was like to go to the hospital.

Some siblings may not want to share their concerns or feelings in order to protect their parents from becoming upset. However, siblings need to know that they can talk about their feelings without being judged or causing a parent to become upset. Talking about an affected sibling can also help show children that their emotions are acceptable.

Spend quality time with all your kids and carve out some special one-on-one time with your unaffected children.

How can I talk with siblings?

When talking to a sibling about DBA, consider the developmental stage of the child. All siblings may not be able to understand the same explanations. Consider spending time with each child and tailoring the explanation based on the sibling's age and specific questions. Focusing on feelings can help well siblings cope with the diagnosis of DBA. Take the time to sit together, listen, and explore what the child is feeling. Setting aside time for talking can help children build coping skills and know that their feelings are acceptable. Here are some examples:

Recognize feelings: You seem upset, sad, angry.

Validate feelings: It's okay to feel that way. This has been hard on you, hasn't it?

Show empathy: I'm sorry. I'll bet that feels terrible. That must be hard for you.

Share your feelings, both positive and negative: I feel that way sometimes too.

Parents may find it difficult to predict how a sibling will cope with a brother's or sister's disorder. You can provide support by spending time with siblings, listening and talking with them, and providing age-appropriate information on DBA. Since the severity of DBA and treatment changes over time, be sure to update siblings regularly. Additionally, you may find it useful to inform teachers about a sibling who is hospitalized or needing treatment. For more information on helping siblings, talk with your hospital's child life specialist or social worker. Another helpful resource is your hospital or local library.

Are there resources to help my family?

Here are books and web sites that others have found helpful:

Books

Parenting Children with Health Issues: Essential Tools, Tips, and Tactics for Raising Kids with Chronic Illness, Medical Conditions, and Special Healthcare Needs, by Foster W. Cline, MD, and Lisa C. Green.

Young People and Chronic Illness: True Stories of Help and Hope, by Kelly Heugel.

What about Me? When Brothers and Sisters get Sick, by Allen Peterkin, MD.

Websites

Sibling Support Project www.siblingsupport.org

Band Aides and Blackboards www.lehman.cuny.edu/faculty/jfleitas/bandaides/

National Association of Sibling Programs (NASP) www.archrespite.org/fs23.pdf

Starlight Children's Foundation www.starlight.org

Diamond Blackfan Anemia Foundation (DBAF) <http://www.dbafoundation.org/>

DBA Nurse Hotline

For answers to questions you might have about DBA, you can call the DBA nurse, Ellen Muir, RN, MSN, at **1-877-DBA-NURSE (322-6877)**.

For more information on DBA: www.cdc.gov/ncbddd/dba

