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Before You Go...  
How to Identify and Train Another Caregiver

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How often have we heard to “just read the instructions” and we will know how to do it? Well, we all know that is not always true. First, our children were born without the “how to” manual. Then the bleeding disorder came along. So much for the worldview of what is often referred to as the “normal” family. Now how do you make sure there is time to do adult things without the children and feel confident leaving them with someone else? There are also the feelings of guilt about leaving your child with another caregiver, possible loss of privacy, fear and anxiety related to the separation. Well, there isn’t a manual for this either. So what is a parent to do when it comes to finding childcare when you go to work, need an evening out or just want to go to the grocery store alone for once? How do you identify these individuals and train them to care for your child with a bleeding disorder?

Though this task may seem overwhelming it may actually be easier than you realize. Think about those in your life who you would trust with one of your most precious possessions, like your child. What qualities in the individuals make you trust and respect them? Some of the things you might want to consider are: do they like children in general and mine in particular, do they have children of their own or have they ever been responsible for another person’s child, are they flexible yet firm when they need to be, will they be appropriately vigilant, and most important, are they level-headed enough to be able to handle an emergency? Now that you have identified some options, where do you go next?

If you still feel uneasy about identifying and training someone to care for your child remember that your treatment center staff is only a call away. They can help you brainstorm through this process as well as helping you identify what important facts related specifically to your child the caregiver needs to know. Too much information can be as scary as not enough. Caring for a child with a mild bleeding disorder may require different instructions than a child with severe hemophilia, an inhibitor or an active bleed. In all cases, one of the most important things to remember is that others take clues from you. If you are comfortable and confident in what you say and do, others will be better prepared to take your lead and feel more comfortable. As you have integrated a bleeding disorder into your life, you now have the task to help others develop that same “can do” philosophy. You just need to teach them the tricks of the trade.

So what do you do when that individual who “always means well” wants to watch your child but you have second thoughts? Try to identify if it is a fixable situation. Is it because they have different parenting styles, limit setting abilities, values or a fear of the unknown related to a lack of knowledge of bleeding disorders? Depending on the individual some of these things may be fixable. Empowering someone with an increased knowledge in bleeding disorders should not be a problem, however, trying to change the way they set limits may be an issue. This can be especially true with well-meaning relatives. Your treatment center staff may be able to help you decide what issues to stand firm on and where you can be more flexible. Remember, you must have realistic expectations. Parents are usually the experts when caring for their child. If you have a “superior aura” that no one else can possibly do things exactly as well as you can, and you expect that, you are setting everyone up for failure. The same principles hold true for the individuals who are petrified to care for your child. Is it fixable or is it better to let it go without hard feelings? Sometimes with time, patience, understanding and your good example, things may change. If not, it is probably better that they don’t care for your child.

Consider the following when training another caregiver:

1. Treat the child with a bleeding disorder as normally as possible.
2. Anticipate age-related behavior with appropriate limit setting. Involve the child in decision making when possible.
3. Provide a child-safe environment that is age-specific with adequate supervision.
4. Discourage introducing new activities while you are away. A first time trip to the playground for a child may be a bleed in waiting. This will end up not being a privilege, but a disappointment for the child, parent and a caregiver who may feel too guilty to return.
5. Provide basic instructions about the bleeding disorder and what to do in specific instances. Be straight and to the point. Remember too much information is as bad as too little. Give them hints about what to look for but don’t expect total body checks. NHF has several small pamphlets that are good for basic information.
6. Remember accidents are just that. Sometimes no matter how hard we try they still happen; maybe because we tried too hard. If the situation is correctable, fix it and move on - no hard feelings. It could have happened when you were there.
7. Have a clear emergency plan; what to do in specific situations, where you can be reached, when to call you, the doctor, or go straight to the hospital. What to take, factor, port supplies, treatment letter and most important a notarized letter stating the caregiver can obtain medical attention for the child in your absence. Have this information in writing where it is readily available.

8. If your child had a recent bleed, is recovering from one or has a hematoma you are watching, be upfront with the sitter. They need to know if it was there before they came.
9. Encourage sitters to let you know of any injury that may cause a potential bleed. This will give you a heads up on what to look for. Remind them, accidents do happen no matter how careful you are.
10. Adolescents can be great babysitters. Ask other parents for referrals. Find out what you can about them ahead of time; can you get references from others they have babysat for? Is there a parent at home that can serve as back up in an emergency; are they willing to do this? Encourage them to take a safe babysitting course. Have them over one or two times to get acquainted with your child and offer basic instructions about bleeding disorders and how they relate to your child. Observe their interaction and interest. The first time you leave make it for a short time and come home earlier than expected to see how things were really going. The state of your home and an inspection of the trash may give you hints as to what went on while you were gone.
11. A good source of sitters may be a referral from a high school counselor or a local school of nursing. Remember you only get what you pay for. If you can't get a free relative you might want to pay a babysitter a little more than the going rate in your community. It will get them to come and work for you before someone else. It's OK not to share the name of a good sitter; you may want to keep them for yourself.

Mary Lou Cygan earned her Bachelors Degree in Nursing at Mercy College of Detroit and her Masters in Nursing at Wayne State University, also in Detroit. She is a Certified Pediatric Nurse Practitioner currently employed at Backus Children's Hospital Hematology/Oncology Clinic at Memorial Medical University Medical Center in Savannah, Georgia. She was previously employed for 28 years at Children's Hospital of Michigan, over 10 years of which were in the Hemostasis and Thrombosis Center of Michigan. Mary Lou has made numerous presentations both nationally and internationally on topics related to bleeding disorders, published several abstracts and articles and has served on national and international advisory boards. She has been active with PEP since its inception participating in pilot programs, serving as coauthor of chapter 1 of the program manual, teaching the program to parents and professionals, and participating on the editorial board and steering committee. The National Hemophilia Foundation named Mary Lou Nurse of the Year in 2000. Mary Lou's special expertise and knowledge related to bleeding disorders comes from being the sister, cousin and mother of an individual with hemophilia.