

Keeping Family and Friends Informed

Along with the whirlwind of emotions and medical demands after your child's diagnosis, you will probably find yourself deluged with questions, tears, and offers of help from family and friends. Chances are you're being bombarded with phone calls and e-mails from just about everyone in your life, as well as a stream of visitors bringing gifts, flowers, food, and even advice. It's natural for people to want to help and stay in the loop – but, however well-meaning, the overtures can sometimes be overwhelming. Responding to so much attention from others while coping with the emergency at hand can become still another challenging task.

One parent recalls the stress and exhaustion of those first days after diagnosis – and at this worst of all possible times she was constantly fielding phone calls! What she desperately needed was to focus on taking care of her son, but it seemed everyone she knew wanted to know what was going on. Not only did she have barely a minute to spare, but telling and retelling the story of her child's diagnosis was nothing short of traumatic.

There are several strategies you can use to communicate with others while still reserving your time and energy for your sick child and family.

One of the best ways to keep people informed, especially if you have a large network of friends and family, is to start a blog or website dedicated to updating folks on your child's progress. This website will enable loved ones in your life to “check in” on you and express their support without calling you constantly. It will free you up to focus on your family, as a few minutes of typing will instantly update everyone you know! Some parents appoint a very close relative or friend to handle the updating of the website or blog for them.

The most popular websites for this type of communication are [CaringBridge](#) and [Care Pages](#), both free and managed by non-profit organizations for this specific purpose. If you think one of these sites might be for you, browse both, because their formats are very different. However, both are extremely user-friendly, even for inexperienced internet users, and easy to set up. You can post journal entries as many times as you want-- hourly, daily, weekly, monthly ... whatever suits your needs. These journal entries are instantly sent to the e-mail inbox of anyone who subscribes to your child's site.

You can also upload pictures, set up links to other websites of interest, and, most importantly, receive messages in the online “guestbook.” You will find that the messages in this guestbook become lifelines at times -- knowing there are so many out there that care about your family can be very comforting. If you wish, you will also be able to connect in this way with other neuroblastoma families. This can become an important source of support and information, as it will enable you to build a network of resources that will last throughout your child's treatment and beyond. See “Finding Other Neuroblastoma Families.”

There are also sites available for forming your own blog, such as [Blogspot](#). You might like to try one of these if you want more control over your own format, but it will probably take a little more time to put together. One downside of a blog is that anyone in the world can view it with a little googling, making it more public than a CaringBridge or Care Page, since a viewer must be aware of and register with the latter services. Just know there are many choices when it comes to blogs, and setting one up will save you time, energy, and emotion. You may even find that journaling your experiences publicly will itself be therapeutic, allowing an outlet for your emotions on good days as well as difficult ones.

A similar option is simply creating an e-mail group. This operates in effect like a blog, but is considerably more private. You select the recipients of your e-mail by creating a group, and hence the people receiving your child's updates are those you approve (and whom you can advise on whether your updates should be further circulated or not). Although you can create some filters on a blog or website, your own e-mails are always more restricted. Another plus is that each e-mail can be tailored for a specific set of recipients. You can select your group based on the particular message, giving you even more control of the information you send.

If you don't have internet access handy, or if talking to people helps you cope, consider a phone tree. By "assigning" calls to several persons closest to you, you can create a communication circle that still gives you extra time. For example: you call only your parents, in-laws, and best friend. Your parents call your aunts and uncles, your in-laws call your husband's sibling and grandparents, your best friend calls your closest work colleague and college roommate, with each of them calling other designated persons, and so on. This way everyone is informed without keeping you away from the person who needs you most -- your child.

Don't forget the power of your child's own words and messages in keeping people informed. When he or she is up to it, consider helping your child create cards, send e-mails, update your website, or make phone calls to people they want to talk to. Many children feel bombarded by the constant attention during their treatment. Reciprocating the gesture may help them sort their emotions.

Whatever decision you make regarding how you communicate, be sure to keep a record of who should be contacted if there is an important update. Don't forget your child's "extended family" - e.g., pediatrician, teacher, soccer coach, etc. Also include your or your spouse's co-workers if possible. Ensuring certain important updates are communicated can be invaluable when you are required to be away from work due to your child's treatment needs.

Finally, don't be afraid to make your own needs known. If you are too harried or preoccupied for calls and visitors or to keep others in the loop, or if you need a specific type of help, don't shrink from letting people know. Many people are desperate to help but have no idea what is needed -- and sometimes there are people who do not grasp what is not needed. You have too much on your plate to worry about the perceptions and needs of so many others. Doing what is best for you and your family is the goal of those who really care about you, and such people will understand if you have no time for them or share that a particular thing is not helpful.

It can be hard to find the time or the words to communicate your needs to others. Sometimes a close friend or family member can help run interference. One aunt, after helping her family during her niece's three-year battle with neuroblastoma, put together a list of suggested ways to help the family of a sick child, as well as a list of things not to do. This list can be distributed to friends or perhaps can just give you some ideas. See "Reaching Out and Accepting Help."

There is no right way or wrong way to communicate with others about your child's treatment and your family's needs. Each of us is unique in our preferences and the amount of privacy or support needed. Of course, whether stressful or comforting to you, it is very likely that throughout your child's treatment you will continue to receive calls and messages from people who want to know how things are going. On the one hand, these inquiries come because people care so much about you and your family -- so, although it doesn't always make your life easier, do keep in mind that family and friends have your best interests at heart and only want to help and be involved. On the other hand, keeping everyone in the loop may at times become difficult for you to handle. We hope the suggestions included here will help you find ways to strike the right balance and relay messages and information to all those who care about you, yet still maximize your time with your sick child and family.

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