

Sample letter to help guide newly diagnosed families about communication

Dear Parent,

You are facing the difficult news of a cystic fibrosis diagnosis. This is not an easy time for you or your family. Here are a few things that we'd like you to consider as you work through the news.

1. There is a lot of hope for children diagnosed with cystic fibrosis today. Medical treatments that are currently available and in development are increasingly helping people with CF to live healthier, happier, longer lives. Be careful about what you read online. Much of the information is extremely dated. The best source of current information is www.CFF.org. Of course, we are here to answer your questions as well.

2. Consider carefully whom you want to share this information with. Once the news about your child's diagnosis is shared with extended family members, friends, and others, it's difficult to control the information.

Some families and individuals are very open about the diagnosis, their feelings, and needs for support. Other families and individuals prefer privacy. Research shows that there is no one right way for all families. Research also shows that families who agree on the approach have less conflict and problems with communication down the road.

It is important to have this discussion and create specific agreements with your spouse or partner. If you are unable to come to a mutual agreement about how to share your private information, please contact us for guidance.

As you disclose your private information including medical details, your feelings, and needs for support, be sure to state your boundaries and needs for privacy. Be clear and direct about whether or not this information can be shared with other people. If you want privacy, make this clear.

Some families who choose the "open approach" control their information by creating a webpage through a third party such as Caring Bridge (careingbridge.org). Friends, family, and extended community members can visit your page and receive the information you choose to share.

3. Be aware of the risks associated with today's technology. When you post anything online, it is there forever. Whether you blog or share information on Facebook or tweet, be aware that it is possible for your child to someday read what you've written. Even if your child is a newborn, ask yourself: "Is this something I would want my child to read someday?"

4. Get plugged in to the CF community. Research is clear about the importance of learning about CF care and learning ways to cope with the challenges that any medical diagnosis brings. There are many ways to connect with the CF community including educational resources, support groups, advocacy, fundraising, and sharing day-to-day joys and frustrations with one another. Take the time to find your niche.

5. Anxiety, grief and depression are common reactions to any medical diagnosis. If you are experiencing intense feelings for longer than a couple of weeks, talk with your CF team about it. We are here to support and guide you. Developing a positive relationship with your medical team will help you, your child, and your family live well with CF.

Please note: this letter is the result of research done by Lisa C. Greene for her master's degree. Feel free to use this but if you share with other professionals, please show credit. Thank you. You can contact Lisa at: lisa@happyheartfamilies.com