

COMMUNICATION PLAN

Phone

During hospital stays, decide when and if you want to receive phone calls. Be clear about your wishes. Give your family and friends set hours to call so as not to interfere with doctors rounds or nap times. Sleep can be hard to come by, the last thing you want during a nap is to be disturbed by a ringing phone. Turn off your cell phone and take the hospital phone off the hook if necessary.

It may be in your best interests to find a trusted friend who can start a phone tree for you. This person will be the one person you keep updated. Ask this friend to become your contact point. Give them an update on your child's situation along with a telephone or email list. After your contact person has made one initial set of calls to pass on the news, they can ask your friends to contact them, instead of calling you directly for updates. Keeping family and friends updated can be as simple as making one phone call.

Journaling

All of our parents agree that the very best method to update friends and family about treatment is to have a web page. Journaling on-line can be a very healthy outlet for parents as it offers an opportunity to let out your feelings in a constructive manner.

Writing down your experience first hand gives you control over how much information you pass on to friends and family. It also provides protection against stories becoming exaggerated. Providing a web page gives family and friends the ability to check on your progress at their leisure. They also have the ability to leave you messages of encouragement.

"I would appoint one person to be the official spokesperson. I found that when I talked about it so much that it would either make me think too much about it and get depressed or mad or I would minimize what was going on so much that I would make someone angry with me because they thought I was purposefully leaving them out of the loop of what was going on. If you can't set it up to be just one person then assign certain people to talk to certain friends and family".

– Kim

"I created a web site, it's a wonderful way to update loved ones on appointments, test results, chemo etc. without having to repeat it over and over to everyone when you may just want to sleep".

– Cheryl

"It beats sending out emails and potentially forgetting someone."

– Scott and Jennifer

Web site

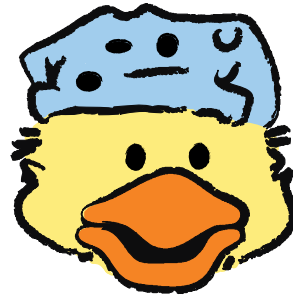
There are several free web hosts with web sites designed especially to keep friends and family updated about your child's medical progress. These follow a format that are very user friendly and have security keys in place so you can decide who has access to your web page. Journaling through an organized website allows you to become part of an online support community of parents if you so choose.

The other option is free web-log or "blog" sites. These are free and do not have a pre-set format. They function as an online diary but are generally not as user friendly for those of us not used to the internet (these sites are listed on the resources page).

"It might sound crazy but I started a journal for Alex from the night she was diagnosed. I wrote a letter to her and I think that was what kept me going. I've got pictures in it from when she was in hospital. Me and Alex still go through the journal and talk about it. It still makes me cry and breaks my heart to see what she went through".

– Rachel

gabe's
CHEMO DUCK
PROGRAM



CONTACT LIST/PHONE TREE

MAIN CONTACT _____

PHONE _____

EMAIL _____

RESPONSIBLE FOR CONTACTING FRIENDS/FAMILY BY EMAIL/PHONE:

SECONDARY CONTACT _____

PHONE _____

EMAIL _____

PLEASE CONTACT:

MAIN CONTACT _____

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