



Advice For Family And Friends

*CHERUBS – The Association of Congenital Diaphragmatic Hernia Research, Advocacy and Support
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- Listen. You don't have to say anything, just lend an ear and a shoulder.
- Learn about the child's problems and how to help take care of him/her. The parents will need trained babysitters that they can trust.
- Avoid saying things like "I understand", "It's God's will", "You just have to accept it and move on", and other cliches and "words of wisdom". Stay positive and respect the parents' decisions and feelings.
- Offer rides to the hospital, babysitting siblings, doing laundry, cooking meals, cleaning, picking up mail, making phone calls, etc.
- Encourage the parents to talk about how they feel, but don't push them too hard.
- Realize that the parents will need support, comfort, and help for many years, not weeks.
- Ask questions, find information, seek support for the parents - but realize that there are certain boundaries.
- Bring food, books, and magazines to the hospital.
- Take pictures, videos, and help the parents to accumulate mementos.
- Throw baby showers, help decorate the nursery, buy the baby gifts - just as you would if the baby was healthy.
- Don't be afraid to cry too. The parents know that their family and friends are hurting too.
- Don't expect everything to be "normal" someday- accept the child for who he/she is, an individual.
- Call the baby by name, not "John and Mary's baby" or other such references.
- Talk to your children about the baby and about what is going on in words that they can understand so that they won't be scared of the baby.
- Let the parents grieve in their own ways - even parents of survivors need to grieve.
- Ask the parents what they need and make them feel comfortable enough to let you know.
- Don't criticize the parents if their child is developmentally behind or not eating with words like "Isn't that baby eating yet?", "Why isn't he/she gaining weight", "A year old and not crawling yet?".
- These children cannot be compared to healthy children or even other CDH children. They have their own paths to follow and reminding the parents that their child isn't "normal" is very painful.
- Something that really bothered me that a relative did was to suggest in her own words to terminate the pregnancy. She felt she had to say something, even if it was just to let us know that we had a choice. The thing is, that every doctor, nurse or specialist we spoke to also told us. The last place we wanted to hear it was from those close to us.
- Don't try to cheer up the parents if they break down crying in front of you...sometimes we need to cry and be sad. Sometimes trying to cheer us up just makes us feel worse.

Suggestions by Danielle Kessner, Theresa Wellman, Dawn Torrence, and Tammy Spohr