

HOW NURSES CAN HELP NEW PARENTS



"A few days after receiving the news my baby had Down syndrome, I was sitting beside my son's crib in the NICU crying. He had surgery the day prior to repair a bowel obstruction and I was overwhelmed. A nurse came over to me and placed her hand on my shoulder and said, 'Honey, I know you are sad now and that's typical. One day this will be your new normal and you will be fine.' Her kindness was reassuring. I have never forgotten her words"

Nurses can help parents cope after receiving a Down syndrome diagnosis. You can be a wealth of support by following these suggestions:

- Congratulate the parents on the birth of their beautiful baby by using the baby's name, if known. Be calm, comforting and reassuring.
- Make sure the family has a "New Parent Packet" from DSAV to take home with them.
- Be familiar with the facts about Down syndrome. Allow them to hear their thoughts and concerns.
- Give parents the information they are requesting. Sometimes too much information is overwhelming. Take their lead, some parents crave information on and others are not ready to hear everything at once.
- If you are unsure of how to answer a question, share that you do not know the answer and that DSAV can answer any questions that they may have.
- Help the mother breastfeed, if she chooses. DSAV can provide information on breastfeeding a baby with Down syndrome.
- Some parents find it helpful to talk to another family that has a child with Down syndrome. Mention that DSAV has a Parent Mentoring Program.
- Respect the feelings that the parents have during this time. Some may cry or be angry, while others are completely accepting. Often times, grieving will occur at home. Seek the advice of a social worker should you feel it may be beneficial.



Simple narrative when conversing with parents immediately after they receive a diagnosis:

"Good Morning! Congratulations on your new baby. Have you chosen a name for your daughter? Emma, what a sweet name."

After small talk acknowledge that you are aware that the baby has been diagnosed or is being tested for Down syndrome by stating:

"Dr. Smith shared with me that Emma may have Down syndrome. I am not sure how much knowledge you have about Down syndrome, but I'd be happy to share with you what I know about it and give you information from the Down Syndrome Association of the Valley."



Why having this conversation is important:

Of course as a nurse you are aware of the diagnosis. You are a key point of contact for the new parents. Those first few days are difficult and they rely on you for care and support during their hospital stay. It is so important to reassure the family that although this is a difficult time, no one knows what the future holds for any newborn baby. Remind them their child is a baby first, and that is all they need to focus on for the time being. There will be plenty of time to figure out everything as their child grows. Family, friends and professionals will help them along the way.

Leave the family with concrete plans on how to proceed at this point. These plans should include:

1. Confirming the diagnosis
 - Chromosomal study: Consider an evaluation by a clinical geneticist
2. Evaluations needed now or in the near future
 - Echo-cardiogram
3. Follow up plan
 - Home nurse visitation
 - Breastfeeding support, if needed
 - Early weight checks
 - Clinical genetics evaluation
 - Cardiology evaluation
 - New Parent Packet from DSAV
 - Share the Ohio Department of Health Down Syndrome Fact Sheet for additional information and resources (www.odh.ohio.gov)



What parents want to know:

- What is Down syndrome
- What causes Down syndrome
- What does it mean for a family to have a member that has Down syndrome
- What are the expectations for a child living with Down syndrome
- How to find balanced, accurate and current information
- Contact information for local parent support groups and community resources



Newborn Medical Care issues:

- Hearing issues - newborns should be evaluated for congenital hearing loss with a hearing test
- Vision issues - newborns should be evaluated for eye issues within the first six months
- Heart defects - a cardiac evaluation and echo-cardiogram may be recommended for newborns
- Thyroid issues - babies should have a blood test at birth, six months and one year to check for hypothyroidism
- Gastrointestinal issues - babies may experience gastroesophageal reflux, or have more significant gastrointestinal issues such as Hirschsprung disease or duodenal atresia

