

CENTER FOR FETAL THERAPY

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JOHNS HOPKINS
MEDICINE



Center for Fetal Therapy

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Living with Hope While Living with Uncertainty

You are not alone. Having a baby diagnosed with any condition can be a very difficult time. It is a time of uncertainty. Living in that space can be challenging, especially when life around you is still going on. Many families have other children at home and many need to re-locate closer to the hospital all while life continues to go on. *Here at JHH we care for the whole family.* We want to support you, the parents, to be as emotionally sound as possible during this time of uncertainty. Below are some points on how to cope and what may happen during this time.

Allow yourself to feel. Cry, scream.... hit a pillow. Then close your eyes and take some long slow breaths.

Ask questions. Then ask more questions. You are embarking on a new world with a new language. The language of medicine. Ask for clarification when you aren't sure you completely understand what was said. JHH treats many rare conditions and we understand that this is all new to many of our patients. Even patients that are physicians or health care providers. Each specialty has its own language.

Allow yourself to accept help. During a medical crisis or living with a long term chronic condition can feel like too much to handle. Embrace the help family and friends offer. People typically want to help. It makes them feel good so allow them to help you so you can help your family. If a friend can take your 5 year old to soccer so you won't miss your appointment, let your friend take your 5 year old. Speak with your social worker about additional resources that may be available as well. There are many organizations created by people who went through what you and your family are going through and have tried to fill a niche that wasn't available for them during their crisis.

Your emotional health is important to the whole family. Seek counseling. Speak with your social worker. Social workers can provide supportive counseling as well as connecting you with a long term clinician and or family/couples therapist. Social workers can also link you with others that have gone through this as well as support groups.

Finances. Please speak with your social worker if you are having issues paying co-pays, high deductibles, parking, lodging etc.

Friends and Family. With any type of change in health, change in relationships can occur as well. Some loved ones are capable of 'being present' with loved ones in difficult times. Other loved ones, for whatever reason, are not emotionally available. This change of relationship status can be unsettling. Know it is not you or your baby but their own ability to handle difficult times.

Additional Support Resources

Caringbridge.org

A website that privately allows you to update your friends and family on how you and the baby are doing. This site relieves the need to text or call numerous people to update. It is a one stop site for family and friends to log on and see how you and the family are doing.

Seleni.org

Website with articles on perinatal mental health.

Sidelines.org

Website offering peer support for women with a high risk pregnancy

Gilchrist

An organization that offers in home counseling and support to families with a high risk pregnancy that live in Baltimore, Baltimore County, Howard County and some areas of Anne Arundel. No cost to the patient or family. Please call 443-630-5523

Chaplain and Palliative Care

Johns Hopkins has chaplains available 24/7. Chaplains are available for prayer as well as emotional and spiritual support during your hospital stay. They can also provide baptism or blessing. If you would like a visit from a chaplain, please ask your nurse to page the on-call chaplain. In addition, the chaplain for the Neonatal ICU specializes in perinatal palliative care and often works with families who have received a discouraging prenatal diagnosis to help with birth planning and decision-making. Your provider can make a referral.

Johns Hopkins WMDC

Johns Hopkins specializes in mental health during pregnancy and postpartum. If you would like to see one of our perinatal psychiatrists please speak to your social worker to help with the referral process.

For additional support, please speak with your social worker.

