CARING FOR A CHILD WITH CONGENITAL HEART DISEASE: *PRACTICAL TOOLS AND RESOURCES*

By Debbie Hilton Kamm

This is second in the series of two articles by Debbie Hilton Kamm, the co-founder and president of California Heart Connection, a nonprofit support network for those with heart defects. She is also the creator of the HLHS Information Page (www.HLHSinfo.org), a site for parents expecting a child with Hypoplastic Left Heart Syndrome (HLHS). The first article, "Receiving a Child's Diagnosis of Complex CHD: Parents' Perspectives and Communication Tools," appeared in December 2005. She has a 5-year-old son with HLHS and Total Anomalous Pulmonary Vein Return (TAPVR), who underwent the 3-stage surgeries and vein repair. She has a Master of Business Administration and a background in health care marketing.

Introduction

Parents of children with complex congenital heart disease (CHD) have the difficult task of understanding their child's medical condition and learning how best to care for them. Unfortunately, many parents of children with CHD have significant knowledge gaps[1] that may impact care, possibly due to a lack of understanding or remembering important instructions. Some hospitals provide excellent detailed care manuals upon discharge from surgery to help families care for a child post operatively.[2] These types of materials have broader applications and may be beneficial for children who have not been hospitalized, or have not needed surgery. Any parent responsible for administering medications, identifying the signs and symptoms of congestive heart failure, coping with feeding and developmental issues or other heart-related concerns can benefit by receiving clear written instructions and comprehensive resources. Physicians who provide this information can help decrease parental anxiety and help children receive the best care possible.

This article presents practical tools physicians can use to help parents during two critical timeframes: preparing for a child's heart surgery, and caring for a child at home. It is based upon hundreds of interactions with parents through:

- California Heart Connection (www.caheartconnection.org)
- The HLHS Information Page (www.HLHSinfo.org)
- online support forums
- and personal experience caring for a now 5-year-old child with Hypoplastic Left Heart Syndrome (HLHS).

Handouts and forms referenced throughout the article have been created to improve communication with parents regarding the care of their child and can be downloaded for free from www.caheartconnection.org.

Prior to surgery

Preparing A Child For Surgery. (Handout) Preparing for surgery is an emotional and anxious time for parents and children. Providing simple instructions for what to bring to the hospital and suggestions for children of different ages can make this time much easier. Tips such as making sure young children are used to eating clear liquids and foods well before surgery can help with the pre- and post-op feeding requirements. Toddlers can be taught simple sign language prior to hospitalization to help them communicate their needs and not feel isolated when recovering from surgery. This handout provides valuable tips for parents and outlines services provided by social workers and child life specialists in preparing a child for surgery.

Medical Specialties. (Form) Many families are confused between the roles of the many medical professionals they may encounter. Providing a handout with the titles and roles of each medical personnel and appropriate questions for each will help parents get answers more quickly.

> ***"This should be required reading for all physicians (let alone parents)…. A well-informed parent makes our jobs easier. Honest discussions covering all issues only serve to prepare parents and avoid surprises or misunderstandings."***
> ***~Edward L. Bove, MD***
> ***Head, Section of Cardiac Surgery***
> ***Director, Pediatric Cardiac Surgery***
> ***University of Michigan***

Support. Connecting with other parents who have children with CHD can provide much needed support and information. Physicians may create their own patient contact list, or refer families to an established support network. Physicians are encouraged to contact support organizations to determine if the information and support provided is appropriate for their patients.

The following support organizations offer information, parent-matching and online support groups in addition to the other listed services:

- California Heart Connection – events, downloadable handouts and forms. www.caheartconnection.org
- Little Hearts, Inc. – newsletter, stories, large annual picnic. www.littlehearts.org
- TCHIN – portrait gallery, list of local support groups. www.tchin.org

At Home

Caring for a child with congenital heart disease can be daunting for parents, whether or not the child requires surgery. Parents are sometimes told to "Treat the child normally." However, they are expected to know the signs of congestive heart failure, watch for developmental delays, and administer multiple medications – far from the norm for most parents. Parents need clear, written information on medications, signs to watch for and available resources to which they can refer as needed.

Home Monitoring Tools

Pulse oximeters and scales. Some hospitals have found improved survival of infants post Norwood when parents were given a pulse oximeter and scale to monitor the child's oxygen saturation levels and weight daily.[3] The home use of pulse oximeters can alleviate the parents' anxiety about having to identify cyanosis, especially in cases where children may not exhibit obvious signs of this condition. The lower cost of handheld units is making pulse oximeters more accessible to families. Some insurance companies will pay for their use, or some families may choose to invest in one themselves if their insurance will not cover the cost. The home use of pulse oximeters for children with complex CHD can help reduce parents' stress levels and help them to identify when to get prompt medical attention for their child.

Sound and Motion Monitors. A major source of stress for parents is lack of sleep, often due to worrying about the child throughout the night. Sound and motion monitors sound an alarm if no motion is detected for a certain period of time. While there is a slight risk of occasional false alarms, they may be reduced or eliminated completely by placing the sensor on top of a plywood board under the mattress. Most parents are more than willing to accept the possibility of a few false alarms to be assured of their child's safety throughout the night. Getting more sound sleep is essential in reducing anxiety and stress levels, and helping parents care for their child more effectively.

Emergency Information

When to Call The Doctor. (Form) Parents are often confused as to what signs and symptoms warrant a call to the doctor or to 911. This form allows physicians to give clear written instructions to the parents to have on hand for future reference.

Emergency Information Sheet. (Form) This form can be filled out and kept at home, in the car, at child care, school, etc. to give to medical personnel in case of an emergency.

Medic Alert bracelets. (www.medicalert.org) These bracelets can be invaluable in relaying emergency information to medical personnel if an Emergency Information Sheet is not readily available, the parents are not present, or if they do not accurately recall important information during a crisis.

Medical Information

Medication Summary. (Form) Parents are often confused about the functions and possible side effects of their child's medication.[1] They may not know what to do if a dose is missed or regurgitated, or when medications should be discontinued. This form lists common medications used for congenital heart patients and has space for any special instructions such as over-the-counter medications that should be avoided, and circumstances under which medications should be discontinued (such as aspirin during fever or prior to surgeries, where appropriate).

Dental Health. Parents may not realize the importance of good dental health for their child with CHD or they may be reluctant to subject the child to additional procedures such as teeth cleaning. However, good dental health should be emphasized for children with CHD. Poor dental status has been found to occur frequently in those with CHD and daily activities such as eating, chewing and brushing teeth represent a major risk.[4] Length of time on digoxin has been found to be significantly correlated with the prevalence of dental caries.[5] In addition, parents' lack of knowledge of antibiotic prophylaxis and lack of compliance can put their children at risk of infective endocarditis.[1] The American Academy of Pediatric Dentists (AADP) suggests: cleaning the baby's gums with a soft infant toothbrush and water starting at birth; the first dental visit by the first birthday; and a dental check-up at least twice a year for most children. Rinsing or brushing a child's teeth after administering oral medications may also promote better dental health. Parents should be made aware of these suggestions due to the increased risk of caries and infective endocarditis in the CHD population. Good dental hygiene may also prevent future dental procedures that may require anesthesia, for which CHD can be a complicating factor.

Follow-up Care

Follow-up Care. (Form) Remembering all of the types of follow-up needed can be difficult for parents as they become consumed with the child's daily care. This form allows parents to have a written timeline of future appointments, testing, lab work and seasonal shots such as the flu and RSV vaccines. It can be used as a guide to answer questions pertaining to follow-up care and as a reminder of future procedures which may help increase compliance by parents.

Feeding and Developmental Concerns

Infant Feeding Issues. Many parents feel great frustration when their baby or child has difficulty eating; they don't understand the connection between feeding problems and the heart condition. They may inadvertently exhaust the child during feedings or underestimate the importance of appropriate caloric intake. Well-meaning family and friends often tell parents, "The baby will eat when he's hungry." Parents should be aware of the connection between feeding issues and CHD and be guided to appropriate resources for help. Feeding specialists available through early intervention programs can help determine the cause of the feeding issue and help the parents with specific techniques to help with feeding. Occupational therapists can help with oral stimulation, oral motor skills and bottle-feeding.[2]

Developmental Concerns. Gross and fine motor delays as well as global delays have been found in children after heart surgery.[6] Infants with CHD have also been found to have a significant degree of hypotonia and retardation of motor development prior to any surgical intervention.[7] Children with CHD often qualify for free developmental evaluations by Early Intervention programs which can help children catch up to age-appropriate milestones. Services are provided regardless of the parents' insurance or income and can often be provided at home, reducing the exposure to contagious illnesses. A listing by state of these free resources is available at: www.nichcy.org/states.htm. School-aged children can often obtain services or accommodations through an Individualized Education Program (I.E.P.) or 504 plan through the school district. See the IEP Guide at www.ed.gov.

Physical Activity Level

Physical Activity. (Form) Physicians should be aware of potential barriers to physical activity that those with CHD face and address the concerns with parents. One study found that almost half of parents studied did not understand the impact of their child's CHD on exercise capacity.[1] Some teachers or coaches may not allow the child to participate in any physical activities, while others may consider the child "lazy" and disregard information on physical limitations. Providing clear written instructions for parents and school officials can help children with CHD participate in appropriate activities, creating health benefits and promoting normal social activities with their peers.

Helpful Products. Physicians can make parents aware of helpful tools that may encourage safe participation in certain activities. Wetsuits for babies and children often help them stay warmer in the water and encourage more frequent swimming activity. Shopping cart covers can reduce exposure to germs, potentially decreasing the risk of illnesses. Their use in grocery stores and restaurant high chairs can help make parents feel more comfortable taking the baby or toddler out in public. The use of chest protectors for use in baseball is controversial, but may be beneficial. Physicians should be aware of products which may be beneficial for certain patients.

> ***"California Heart Connection has compiled an invaluable list of resources to help parents who care for children with congenital heart disease. This information provides answers to the inevitable questions that arise once families have left the hospital or office. We make certain that each new family receives a copy of the Resource Guide."***
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> *~Michael Rebolledo, MD*
> *Director of Echocardiography*
> *Children's Hospital of Orange County*

Conclusion

Parents face the sometimes daunting task of caring for their child with complex CHD. Physicians can help parents understand and retain information while reducing parental anxiety by the use of the tools mentioned above. Making parents aware of the many resources available can reduce their emotional burden and help them provide the best care possible for their child.

The following handouts and forms can be downloaded for free from the California Heart Connection web site at www.caheartconnection.org.

- Preparing A Child For Surgery – handout with tips and suggestions for preparing for a hospital stay.
- Medical Specialties Form – a list and description of different medical specialties with space to provide contact information for each.
- When to Call the Doctor Form – form to be filled out by physician which delineates which symptoms warrant a call to the doctor, or a trip to the ER.
- Emergency Information Sheet – information every parent should have available in case of emergency.
- Medication Summary Form - benefits and possible side effects of common cardiac medications, fill-in area for dosage information and special instructions such as what to do if a dose is missed.
- Follow-up Care Form – timeline for follow-up visits, vaccinations, therapies, etc.
- Physical Activity Form – clarifies appropriate activities for the child with CHD.
- Resource Guide – handout for parents with information on support, medical information, helpful products, Early Intervention services, insurance/financial information, and more.

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