



The **KU Kids Healing Place** in the Department of Pediatrics at the University of Kansas Medical Center provides the best in chronic illness support and palliative care for infants, toddlers, children, adolescents, and young adults living with chronic or life limiting conditions.

In 10th grade, Lily was diagnosed with Ewing's sarcoma, a bone cancer, in her leg. Six months later, she has been given several rounds of chemotherapy, lost her hair, spent 57 days in the hospital, and undergone an extensive limb salvage surgery that saved her leg, but caused great pain and disability. Lily tries to keep up in school, but she is absent most of the time and, when she is in school, she is very tired, and, after extensive absences, is confused about what other students are doing in class. She has had to drop off the soccer team, stop taking dance lessons, quit her part-time job, and rarely gets to hang out with her friends. Her best friend invited her and a few other girls to spend the night for her 16th birthday. Lily called her mom to come and get her about 11 p.m. when all the girls started talking about how they were going to wear their hair from prom. Lily couldn't get into THAT conversation, and who would ask a bald girl to prom, anyway? She just wanted to go home where she felt safe and had no pressure to "fit in".

Jacob is an active 4th grader – except when he is having a sickle cell crisis. He has had a lot of crises lately, and he is tired of always hurting and of missing so much school. It seems like everything is different lately. He used to be the best in his class in math, but he's barely passing math now. In addition, Jacob was a great basketball player – he scored more baskets than anyone else on the playground. His doctor won't let him play basketball anymore, because he says it might cause him to have another crisis. Jacob feels so tired all of the time, and when he does make it to school, he is spending much of the day in the nurse's office. He's also gotten into trouble for talking too much in class and for acting up at school. Sometimes, it seems like too much work to try to keep up with school and do what everyone tells you to do.

Lily and Jacob are two of the 26% of children in the US who were reported to have a chronic health condition in 2006 (van Cleave, Gortmaker, Perrin 2010). Over the past 30 years, the prevalence of chronic conditions in children and adolescents has increased, particularly for asthma, obesity, and behavior/learning problems. Further, former premature babies, children with Down syndrome, and those who have neonatal human immunodeficiency virus 1 infections are realizing greater life expectancies. Youngsters with sickle cell disease, cystic fibrosis, asthma and other diagnoses are surviving longer as treatment and technology improves.

Being a kid with a chronic, life-limiting or life-threatening illness is not easy. Adults may be able to take time off work when they have health challenges, but a student must keep up with their school work, or risk repeating a class or an entire grade. Excessive absences make it difficult to stay caught up academically and socially. When a student is at school, fatigue, medication side effects, and the disease process itself may result in an inability to concentrate. Involvement in sports, clubs, recess, activities or places of worship are limited by decreased strength, energy and time which frequently occur with an ill child.

Often, peers and friends move on and forget to include their friend or may have unspoken fears about “catching” their friend’s illness. Due to the unpredictability of a child’s health status, even family activities may be challenging to schedule. There are many challenges in coping with and adapting to life with a chronic disease, and increased survival cannot be assumed to be associated with increased quality of life. During this time, kids and family need support, understanding and action. Excellent medical care is the first step; caring for the whole child and family, however, requires much more.

Many children’s hospitals and pediatric units offer excellent services and multidimensional care *within* the hospital setting. However, children’s multidimensional needs do not stop when a child leaves the hospital or clinic. Currently, there is not a mechanism to support a child’s multidimensional needs as they transition from health care settings back to the community and their natural environments of school, daycare, worship, activities, sports, etc.

At the **KU Kids Healing Place** in the Department of Pediatrics at KU Medical Center, we have experience in collaboration with community partners to begin the process of providing multidimensional care for children who suffer from chronic illnesses. We provide training, education, and support to teachers, school nurses, clergy, coaches and other education professionals working with these children. The response has been overwhelmingly positive; educators have indicated that the information has been central to helping children succeed in school. It is often said that “it takes a village” to raise a child. Well it takes a village of caring, compassionate and informed individuals to support a child and family through an experience with a serious health condition.

Up until now, services for children have been one-dimensional and have occurred in isolation in various environments (i.e. hospital, home, etc.) and on a limited basis. **KU Kids Healing Place** provides the next step in care for youngsters with chronic or life-limiting diagnoses - comprehensive multidimensional services that will address the unique and individual needs of the child and his/her family in all environments, including the child’s natural environments of home, school, daycare, activities, etc. Care for the child and family is initiated within the inpatient or outpatient setting at KU Medical Center, and will follow the child to his/her community. Training, education and support are provided to health care providers and to individuals who work with the child and family in the community.

KU Kids Healing Place is committed to providing the best in family and child centered care. The goals of our program are in line with the concept of a medical home and include:

- A partnership between the family and the child's/youth's primary health care professional
- Relationships based on mutual trust and respect
- Connections to supports and services to meet the non-medical, as well as the medical needs of the child and their family
- Respect for a family's cultural and religious beliefs
- After hours and weekend access to medical consultation
- Families who feel supported in caring for their child
- Primary health care professionals coordinating care with a team of other care providers

Through this partnership, the primary health care professional can help the family/patient access and coordinate specialty care, educational services, in and out of home care, family support, and other public and private community services that are important to the overall health of the child/youth and family.

American Academy of Pediatrics: <http://www.aap.org/healthtopics/medicalhome.cfm>

Van Cleave, J., Gortmaker, S.L. & Perrin, J.M. (2010). Dynamics of obesity and other health conditions among children and youth. (2010). JAMA. 303(7):623-630.

For more information on this innovative program, please contact Kathy Davis, PhD at kdavis2@kumc.edu or (913) 588-6305.