



Parenting Plus: When Your Child Has IBD

Most parents will tell you that parenthood is the single most challenging role of their lives. Even compared to training for the Olympics, parenting requires development of extraordinary skills and dedication to long-term goals.

Parents of all backgrounds share a common prayer for bringing healthy children into the world and watching them thrive. Yet statistics tell us that 10 percent of children in this country live with some form of chronic illness.

Parents facing the news of a child's diagnosis of an inflammatory bowel disease (IBD)—either Crohn's disease (CD) or ulcerative colitis (UC)—may think that they do not possess the skills or abilities for this added challenge. But experts in the field of IBD have another, most hopeful, perspective to share.



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—Frank Sileo, Ph.D.

Looking at the Whole Person

Frank Sileo, Ph.D., a clinical psychologist and Executive Director of The Center for Psychological Enhancement in New Jersey, embodies the concept of considering the whole person when treating Crohn's disease and ulcerative colitis. Diagnosed with CD himself at age 20, he chose a professional path that would enable him to help children live normal lives in spite of some very serious setbacks. When you speak with Dr. Sileo, known as "Dr. Gutsy" to the children he treats, you are struck with how engaged he is in proactively confronting even the smallest issues. He works with the whole family, because, as he explains, his best treatment would fail if the family could not support the behaviors he is aiming to encourage.

Dr. Sileo works to develop self-advocacy in the child from the youngest age. He treats children even under the age of five with some astonishing results. Through guided imagery and relaxation, he helps them to manage difficult toilet experiences and become kindergarten-ready.

Dr. Sileo explains why families with IBD need to be proactive in looking for the type of support he and others might offer: "This is a very overwhelming experience that causes discomfort, embarrassment and shame. In diagnostic examinations, boundaries are crossed with colonoscopies and invasive procedures. He goes on to explain, "Children may see themselves as defective. They need to be told that they are not their disease. The disease is only one part of so many other aspects of the person that need to be celebrated and fostered." It is the role of a "Dr. Sileo" to integrate all the parts of the

whole and make it healthy. As an alternative to behavioral therapy, he believes that parents should, at the very least, avail themselves of any support group opportunity or create one with the help of their physicians.

Not surprisingly, many parents tend to be overprotective of children with a serious chronic disease. Dr. Sileo cautions his families that this could be a big mistake. Even at the youngest ages—a toddler for instance—should work through developmental tasks. He states: "If you treat your child like a piece of glass, they will act like one." According to Dr. Sileo, the age of the child should dictate parental behavior, not IBD. Discipline does not change. Children need to try out for sports and school plays and modify their roles where necessary to participate. They need to keep up with schoolwork. He encourages children to be fighters and self-advocates and offers his own history as a role model to growing youngsters. He teaches them to ask to "have it their way" when ordering food, without cheese or French fries, and raise the question of toilet location when they are outside of the school building.

Is there a common element that can be identified in successful parenting of children with IBD? Janis Arnold, LICSW, who has become acquainted with over a thousand IBD patients in her job and through CCFA events, believes that outlook and anticipation are key. When parents visualize a good family life and successful future, they are less likely to fall into the trap of feeling helpless and hopeless. Dr. Sileo would add that parents need to encourage their children to see themselves as something other than a medical diagnosis, "that CD and UC are only a part of who they are, not everything."

By laying the foundation for good medical care, developing a functional team and support system, and addressing the broader picture of the whole child and the whole family, parents can indeed get on with the most challenging role of their lives: being parents. ■

Resources Right for You

The following educational publications are available at CCFA's Web site: www.ccfa.org/info/brochures:

- "A Guide for Parents"
- "A Guide for Teachers and Other School Personnel"
- *IBD & Me: An Activity Book for Kids*
- *Pete Learns about Crohn's and Colitis* (educational comic book for kids and teens)

CCFA also recommends *Toilet Paper Flowers: A Story for Children about Crohn's Disease* by Frank Sileo, Ph.D., available at bookstores or at www.ccfa.org/shop.

For online help, check out our "Parents and Caregivers" forum at our free support site: www.CCFACommunity.org.

For other resources, please contact our Information Resource Center, available Monday through Friday, 9:00 am-5:00 pm EST, at 888-694-8872.