

Susan Calhoun

The Whys and Hows of a Support Group

I would like to share out of my personal experience how belonging to a support system enables me and gives me a feeling of acceptance.

I have always thought that it was rather nice to be involved in civic organizations or social clubs, such as a garden club. These groups typically convey a sense of prestige created by being a part of a social or service club. The members can give of their time and talents and have a sense of fulfillment in what they are accomplishing.

In contrast, there usually is a stigma attached to belonging to a support group. The word *support* connotes needing help rather than being able to do it on your own. Especially for a parent of a child with special needs, there may be an additional hesitancy to get involved with such a group. The parent doesn't want to admit that his child might have a disability or acknowledge that he needs help. His time may be limited because of his child, and the stress of one more meeting to attend may not be an option.

Nevertheless, I would like to share out of my personal experience about support—how belonging to a support system enables me and gives me a feeling of acceptance.

THE NEED FOR SUPPORT

I remember the first encounter I had with a support group. My first daughter, Jennifer, was diagnosed at six months of age as being severely mentally handicapped. I was absolutely devastated. I felt like I was isolated from the world with no one to talk to.

One morning I attended a support group sponsored by the developmental clinic where Jennifer was a client. I quickly realized that I was not alone. I heard the moms talk about their successes and heartbreaks with their children. In that room a feeling of acceptance surrounded me.

Jennifer progressed very slowly; however, each milestone was a miracle. I received support through her teachers at school and one parent whose child was also profoundly handicapped. Networking among parents whose children were disabled was not readily done back in the mid-1970s. Support systems for parents were not prevalent, so support was limited.

When Jennifer was 2½ years old, she contracted a virus and was admitted to the hospital for five weeks until her death. I needed support more than at any other time in my life, and yet it wasn't available. My greatest desire was to talk with another parent who had shared my experience. However, I knew no one with a similar experience.

My need for support has continued because of my two sons, who are now 11 and 14. They have a mitochondrial disease, which has resulted in ataxia, developmental delays, and retinal degeneration. In each child the symptoms were evident at the age of two years and have continued until the present time. My support during their younger years was provided by their pre-

school special education teachers and other parents in the school. As the boys have gotten older, the sources of support have broadened—Special Olympics, special education teachers, and friends.

Having children with rare illnesses can isolate parents. Trying to find another parent whose child has a similar diagnosis can be frustrating. My fourth child, Meghan, was diagnosed at the age of six months with a rare brain disease, Leigh's disease. We knew from the onset that her life expectancy was just a few months; yet we wanted to make the months together very special, especially for her two brothers. My husband, Jim, and I were indeed searching for support through family, church, or friends.

While Meghan was in the hospital, she shared a room with a little boy named Christopher Conboy. His mother, Lynne, and I became very special friends. We were dealing with children with involved medical conditions and needed someone to talk to about our feelings. We became important to each other.

Meghan died in early 1983, at the age of 16 months. Christopher died the next month very unexpectedly. In the weeks following our children's deaths, Lynne and I realized more than ever that we needed each other for support. In our early days of grief we found solace in sharing with one another. We realized how important our relationship had been during the months our children were alive.

BEGINNING THE SUPPORT GROUP

Lynne and I were determined to see that our common experience did not end on a note of defeat. We wanted to transform all we had learned into something positive. We realized that we had both met many other parents who did not have a support system. Aware of the immense strain that life with chronically ill children had placed on our marriages and our families, we discussed the possibility of developing a support network for families whose children were chronically or terminally ill.

Before attempting to form a group, we networked with doctors, social workers, and parents we knew who had children with chronic medical problems to get their reaction to our ideas. The idea of an organization to provide emotional support to families with chronically

or terminally ill children seemed to address a genuine need.

In the summer of 1983 the vision became reality and a living and breathing ministry began. FOCUS—Families of Children Under Stress—was developed to provide support for families. Emotional, informational, and physical support are the main objectives of FOCUS.

The FOCUS children have ranged in age from newborn to adolescence. The medical conditions have included cerebral palsy, developmental delays, or speech delays as well as life-threatening illnesses such as immune deficiencies and degenerative neurological disease. FOCUS does not discriminate among medical problems.



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PURPOSE OF A SUPPORT GROUP

What are the goals for our support group and how do we achieve them? We realized from the beginning that emotional support for the families would be our primary objective.

We provide monthly share groups and structured meetings with professionals addressing specific needs of parents. The meetings afford parents an opportunity to share their struggles and sometimes the small victories which keep life going.

Several times a year we have family activities which involve the entire family. It is very important for the siblings to have interaction with other siblings and be involved. On occasion

we have support group meetings specifically for the siblings to address their specific needs.

Upon referral from a physician or social worker, hospital and/or home visits are made with parents whose child has been recently diagnosed. In times of crisis, FOCUS provides that sense of caring that is so essential for parents.

FOCUS has a bereavement support group for families whose children have died from chronic illness. The parents can share their feelings and gain strength from each other as they journey together through the grief process. For the parents who have been actively involved with FOCUS during their child's life, this support network is very important after the child's death.

A hot-line is available for parents to obtain information or emotional support. Just to have another parent to talk to and share your feelings with helps in the coping process.

Informational support is provided for our parents in several ways. A bimonthly newsletter provides a forum for parents to express their feelings about having a child with special needs. It also announces FOCUS activities and lists community resources. The newsletter provides valuable support for many parents who are not able to attend the monthly support group meetings.

An annual conference is held each fall for parents and professionals. It centers on the grief and stress aspects of dealing with a child with a disability and provides tools to help in the coping process. It provides a positive opportunity for dialogue and interaction between parents and professionals.

A resource library comprised of periodicals and books geared toward the family with a disabled child or the family whose child has died is available. The books and periodicals are available at support

group meetings for the parents' use.

The physical support for our families is varied as we try to meet each family's needs. Aspects of FOCUS support have included providing a week of camp in the summer for the child; offering a weekend of respite care; preparing and delivering a meal for the family while the child is in the hospital; or just being with the family whose child is critically ill.

MAINTAINING A SUPPORT GROUP

Maintaining a support group for families is a process that takes tremendous planning from FOCUS Board and Advisory Board members. I have come to believe that FOCUS is a God-given ministry. God enabled me, through my experiences, to be an instrument for Him. I have to rely totally on Him for decisions and direction for our support group.

For many of our parents a spiritual journey is not part of their life. They feel a great deal of bitterness and resentment for what they feel they have been dealt in life. For others, their faith enables them to survive.

FOCUS has touched many lives over the last nine years. The contact with the families has varied depending on the medical condition of the child. Support may not be needed for the family on a long-term basis if the child's condition is resolved. However, for the majority of our children, the handicapping condition is a lifelong situation. The families are planning for the future with these children with a great deal of anxiety.

Many Christians facing difficult circumstances have found comfort in these words: "We know that in all things God works for good with those who love him" (Rom. 8:28). God has provided that comfort for Jim and me over the last 16 years in dealing with the medical situations of our children. I must confess I don't have all the answers as to why these circumstances have happened with our children, nor do I have any answers to the FOCUS parents as to why their children are disabled. I do know that God is always with us, and if we will let Him, He will support us.

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