For generations of American children, summer camp was an annual tradition. Eagerly anticipated or greeted with dread, the image of bus-loads of screaming children heading off to a week or two away from home was simply part of the summer landscape. Yet, while summer camp is no longer as ubiquitous a presence in our culture as it once was, for many families, summer camp still offers timeless benefits to those who attend.

Dr. Shari Delisle, a licensed marriage and family therapist who practices in the San Diego area and specializes in childhood and parenting, says summer camp offers a controlled environment where children can begin to learn to make decisions on their own in a safe setting. “Helping children develop confidence in their own autonomy and competence is the highest parenting duty, however unwelcome a task it may seem,” Delisle explains. “The most fortunate children are those whose parents urged them to become skillful fliers. Sending children off to camp offers a perfect halfway measure for practice in flight. The child knows it is a limited period of time, and parents can resume their rooting work when the child returns to the cozy nest. In that most important interlude, a child learns how to master new challenges presented in the camping experience and [his or] her personal confidence is expanded.”

That growth experience at camp, Delisle adds, is even more important for children with chronic medical conditions. “For special-needs children, this camping experience is crucial to the growth of trust — in self and in the world. Like children without these difficulties, they must also receive the gift of personal autonomy and a sense of personal efficacy, however it is modified to fit the special needs of the child.”

Parents of children with immune diseases and other chronic conditions who have attended summer camps and similar weekend retreats echo Delisle’s thoughts, saying their children benefited from the experience. “He came back a changed boy,” Terry Stone of northern Virginia said of her 7-year-old son, Matthew, who attended a camp for hemophiliac children for the first time last summer. “He made a lot of friends and he’s far more independent. Having a kid with a chronic illness, we ‘mamas’ tend to baby them a bit. This kid was pretty sheltered and
protected. In some capacities, I still overnurture him a little. By him being gone all week and fending for himself and getting to just be a boy, he came back just fine with everything. "I'm going to go get my pajamas on now," "I'm going to go brush my teeth now."

Stacey Henderson sent her two children with ataxia telangiectasia (A-T), an inherited neurodegenerative and immunological disease, to a weeklong camp run by the Muscular Dystrophy Association at Camp Waskowitz in North Bend, Wash.: “The first time they ever went, it was incredible. I think they spent from Sunday to Saturday there, so it [was] almost a full week … [and] both of them cried on the way home; they didn’t want to leave. They wanted the next year to come right away…. They developed a lot of friendships — not just [with] the other campers, but [with] the counselors [with whom they] kept in touch all year long.”

Because Henderson’s children (her daughter passed away a couple years ago) were confined to wheelchairs, finding a camp that could accommodate them was a challenge. Yet, while A-T isn’t muscular dystrophy, the association has adopted this disease to support the children with it, according to Henderson, and invited her children to attend the camp, which they did every year from the age of 7 on. “That time away from the family, it was a great benefit for them because they were able to go somewhere without their family,” she explains. “And they did feel more empowered, I think, that they were able to be away from their family.”

The Format

Like other summer camps, whether in resort towns or run by the Scouts or Girl Guides, camps for special-needs children often have older teenagers serve as counselors to lead the younger campers in their daily activities under the supervision of trained staff. Many of these counselors are former campers themselves, and often they have the same medical condition as the campers. Stone, for instance, says that having older teens and young adult hemophiliacs as volunteers at her son’s camp let him see that his condition was not a roadblock to a happy, active life. As she put it, young children look up to teenagers and young adults in a way that they don’t look up to their own parents. “Matthew had a great comfort level with them,” she explains.

The growth experience at camp is even more important for children with chronic medical conditions.

And, of course, special-needs camps also feature the same types of activities as other camps, such as the one Joanne Pease is coordinating — a weekend family camp scheduled next summer in the Yakima, Wash., area, at Camp Prime Time. Theirs will be a three-day weekend camp, from Friday afternoon to Sunday afternoon, and will include crafts and learning classes for the younger kids, outdoor activities, a campfire and a ride on the lake on a barge, among other things.

What is unique to special-needs camps is the onsite medical care and facilities provided, depending on the needs of the children.

Family Camps, Retreats

Not all parents are ready to send their children off to camp by themselves. In fact, some parents of children with chronic medical conditions are in as much need of a mutual support system as their children. For these families, family camps or retreats are a good alternative to the traditional summer camp.

Many of the family camps operate like the one Pease is organizing in Yakima, which is in demand from area families whose children have primary immune deficiency (her three grown sons all have it). With campers assigned cabins by family and with shared family meals on Friday and Saturday evenings, the parents can enjoy meeting other parents. Their camp also is open to young adults.

Susan Nadrich of Buffalo, N.Y., took her two daughters to such a family retreat last year in Southern California, and said the experience was life-changing for the entire family. “The Painted Turtle was an amazing place,” Nadrich explains. “I learned about it from reading IG Living magazine. [And, while] it was beyond the deadline when we applied, they said ‘apply anyway.’”

Nadrich and her daughters, 7 and 10, who both have primary immune deficiency, were accepted. “The younger had been having a difficult time. To be able to go to the Painted Turtle and get to know other little children with the same illness and receiving the same
treatment [the same infusions every week] allowed her to not only make new friends, but realize she is not alone. For me as a parent, I too was not able to find anyone else going through what we were going through,” Nadrich says. “To meet other parents was just wonderful. I learned about other methods of treatment, some shortcuts, some ways to make it easier on us. I really hope we can return next fall. My youngest made a best friend — they talk on the phone, and they really understand they’re not alone.”

While the Painted Turtle does offer traditional weeklong camps for the children (and Nadrich admitted her youngest has been bugging her to let her go), she says the weekend retreat seems a better fit: “My thought is that we as a family can benefit more from the family events.”

Yet some parents do use the family retreat as an introduction to the camp programs. Stone said that before sending Matthew off to Camp Holiday Trails in Charlottesville, Va., the family went to a weekend retreat because she was reluctant to let him go to camp at all. “We went to family camp, so they got a chance to get to know the family,” Stone says. “We went in May, and I thought, ‘I can check that off our list; he got to have the camp experience, he slept in a cabin.’ [But, when] we came back, he said, ‘I want to go to camp alone.’”

**Education, as well as Support**

In addition to the growth experience of being away from mom and dad for a week, and the relief of making new friends who are different the same way you are, many children learn important life skills at camps for special-needs children. Stone says that at the hemophiliac camp, the attendees are able to earn a “Golden Stick” award if they learn to self-administer their factor — and that Matthew came home with his the first year. “It’s a little more cool; there’s a little more interest when mom and dad aren’t there,” she adds.

**Family camps or retreats are a good alternative to the traditional summer camp.**

Pease believes that often much of the educational benefit from the family camps and retreats comes not from any experts, but simply from sharing experiences in dealing with a chronic condition. For instance, comparing notes can shed light on new ways of dealing with a situation.

**Finding a Camp**

Over the years, quite a few camps have been started that are geared toward children with chronic medical conditions — including many immunological deficiency diseases and conditions. One way to locate a camp for your child is to ask your local support group, such as other parents you know or a nonprofit group dedicated to your child’s condition.

And many mainstream camps will accept children with primary immune deficiency or other conditions that are under control and require little intervention. If there’s a popular camp in your area, ask the camp director about accommodations for your child.

The late actor Paul Newman founded and funded The Hole in the Wall Gang Camp in Ashford, Conn. Every summer, the camp offers a variety of programs for children with cancer and other serious diseases — at no cost to the family. Learn more at holeinthewallgang.org. The Painted Turtle is another Hole in the Wall camp funded by Paul Newman. It is located near Lancaster, Calif., north of Los Angeles. Find out more at thepaintedturtle.org.

Other camps include Camp Holiday Trails in Charlottesville, Va., which serves special-needs children (campholidaytrails.org); Camp Prime Time in Yakima, Wash., which is also geared toward children with chronic medical conditions (campprimetime.org); and the Immune Deficiency Foundation, which is offering two retreats in 2010, one in Rye Brook, N.Y., from June 25-27, and a second in San Francisco from Aug. 13-15 (primaryimmune.org).

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