



Complex Child E-Magazine

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Your Child CAN Go To Camp!

by Susan Agrawal

While all children need to get away from the monotony of every day life occasionally, children with medical needs or disabilities often crave this experience even more. Nothing can be better than time spent away from school, therapies, doctors' appointments, and hospital stays. A great way to let your child get away from it all is to send him or her to overnight camp.

It may be very difficult to imagine that your child can go to camp, but there are camps out there designed for children with almost every type of special need or disability. These camps include intensive medical or self-help support, allowing children to flourish away from home.

Determining the Type of Camp

There are hundreds of camps out there, so the first thing you need to do is figure out what type of camp your child can attend. Here are the general types of camps available:

- **Regular Camp with Supports:** If your child only has minor issues such as moderate asthma or mild cerebral palsy, he or she may be able to attend a regular camp with a little extra attention from the nursing staff and counselors.
- **Medical Camp:** Medical camps, which may be general or condition-specific (such as a cancer camp or MDA camp), are for children whose medical needs would otherwise prohibit them from attending camp. Children usually need significant assistance in one or more areas, including medication administration, tube feedings, IV nutrition or medication, catheterization, respiratory support, nursing services, activities of daily life (toileting, dressing), and so forth.
- **Condition-Specific Camp (Non-Medical):** Children with physical disabilities, visual/hearing impairments, autism, intellectual disabilities, or significant behavioral issues will typically not be able to attend a regular camp or a medical camp, but there are hundreds of camps out there geared toward children with these conditions. Children with autism, ADHD, intellectual impairment, developmental disability, mental health disabilities and similar other conditions typically attend camps with special supports to help guide behavior and development. Children with physical disabilities who do not need significant medical care can attend specialized camps that have activities adapted for children with physical limitations, including children in wheelchairs or walkers.

- **Specialty Camps:** There are not many specialty camps for children with disabilities, but there are some, most of which focus on a specific therapy or technique. These may include camps for Augmentative Communication, ABA camps, Conductive Education camps, and similar other camps.
- **Family Camp:** Family camp allows the entire family to attend as a group. While family camps are available for children with almost any special need, they are particularly well suited to children who are very medically complex and cannot attend camp without constant one-on-one assistance from a parent.

Things become difficult when your child fits into more than one category. A child with autism and significant medical needs, or a child with severe cerebral palsy who is very medically fragile, may have great difficulty finding an appropriate camp. These children's medical needs necessitate that they attend a medical camp, but most medical camps are not geared toward children with difficult behavioral challenges or severe physical disabilities. These children may only be able to attend family camps.

There is a great online resource available to help you determine what type of camp your child needs and to prepare for camp. Sponsored by the National Center on Physical Activity and Disability, it can be found at <http://www.ncpad.org/get/discover/>.

Finding a Camp

A great resource for finding a camp is the website Very Special Camps, at <http://www.verypecialcamps.com>. This website allows you to search for a camp by diagnosis, condition, location, or keyword. Note that this list of camps does not include all the camps available. There are many additional camps, often highly specialized or small, that may not be included.

Another good way to find a camp is to contact the disease organizations that are appropriate for your child, such as UCP or Easter Seals. Ask parents, teachers, and therapists in your area if they have experience with camps. You can also Google your child's diagnosis and the word "camp," such as "cerebral palsy and camp." Sometimes adding your general location can help find nearby camps.

Once you have found what options are available, you need to determine if a camp is appropriate for your child. Here are just a few of the questions you might want to ask yourself:

- **What type of physical environment is necessary for my child?** For example, if your child uses a wheelchair, all buildings and activities need to be accessible. If your child has a visual or hearing impairment, the camp must be designed to accommodate such disabilities. Or, if your child is heat-intolerant, the camp must have air conditioning. Bathing and toileting facilities should be appropriate for children with physical impairments.

- **Are the qualifications of the support staff adequate and the counselor to child ratio appropriate?** Some children will need constant one-on-one support, either due to physical, medical, or behavioral needs. Make sure the program you are choosing can accommodate the level of need your child requires. Also make sure that the person who will be providing support is the appropriate type of individual. For example, a child with a trach or central line may need to have a nurse caring for him at all times.
- **Are the activities appropriate for my child?** Make sure the planned activities are appropriate for your child's specific cognitive, physical, behavioral, and sensory level. Your child does not need to participate in all activities, but the majority should be appropriate.
- **Will my child be safe?** Make sure the camp environment, activities, and structure can safely meet your child's needs.
- **Is transportation to and from camp activities accessible to your child?** Most camps take children on day trips and you need to make sure your child will be able to attend if she uses a wheelchair or other specialized equipment.
- **What medical services are available?** Children with greater medical needs must have access to appropriate medical services. Make sure that your child's needs can be met by the services available.
- **Will problem behavior be dealt with appropriately?** Children with behavioral issues need to attend a camp with appropriate supports and a clear plan for handling behavior.
- **Can I afford this camp?** Many of these programs are free, but some are quite costly. Make sure you know the total of all the costs, including daily expenses while at camp.

A Few Very Special Camps

Hole in the Wall Camps

If your child has medical needs, a great place to start is the Association of Hole in the Wall Camps at <http://www.holeinthewallcamps.org/>. All of these camps are designed for children with medical needs, including children who require tube feeding, chemotherapy, respiratory support, intravenous therapy, or other medical support. These camps include The Painted Turtle in California, The Hole in the Wall Gang Camp in Connecticut, Camp Boggy Creek in Florida, Double H Ranch in New York, and Victory Junction in North Carolina, as well as several international sites.

Most of these camps designate each week for a specific disease or condition, although some weeks may be general sessions. Children with 150 separate conditions are eligible

for camp. This summer, there are special camps for Liver Transplant, Kidney Disease and Transplant, Muscular Dystrophy, Crohn's and Colitis, Rheumatic Disease, Hemophilia and other bleeding disorders, Skeletal Dysplasia, Sickle Cell, Immune Disorders, Heart Issues, Cancer, Epilepsy, Spina Bifida, Craniofacial Disorders, Asthma, HIV/AIDS, Cerebral Palsy, Vascular Diseases, Children with Burns, Gastrointestinal Disorders, Genetic Diseases, and Lung/Respiratory Diseases (including ventilator-dependent children).

Each camp has extensive medical services and can accommodate children on medications, children with feeding tubes and central lines, children who need cathing, and in some cases, children with trachs or ventilators.

All camp sessions last one week and are free. In addition, family weekend camps are available in the spring and fall. These camps are especially good for children with extremely complex medical needs who may not be able to attend without a one-on-one nurse.

- <http://www.thepaintedturtle.org>
- <http://www.holeinthewallgang.org/>
- <http://www.boggycreek.org>
- <http://www.doublebranch.org/>
- <http://www.victoryjunction.org/>

MDA Camps

The Muscular Dystrophy Association also holds summer camps for children with qualifying disorders, including Muscular Dystrophy, Neuron Diseases, Metabolic Diseases of the Muscle, Peripheral Nerve Diseases, Myopathies, Mitochondrial Diseases, and Diseases of the Neuromuscular Junction. For a complete list of conditions, see <http://www.mda.org/disease/40list.html>.

Information about these programs may be found at <http://www.mda.org/clinics/camp/>. Camp is free to all children, and extensive medical supports are provided. In most cases, children are paired with a one on one volunteer to assist with all activities, including daily life skills such as bathing and toileting. Respiratory therapists and physical therapists are available, along with nurses and a physician.

Camps for Children Requiring Respiratory Support

While some of the Hole in the Wall camps and MDA camps can accommodate children who need ventilator support, there are several other camps available that focus specifically on these children. These include:

PA Vent Camp: <http://www.paventcamp.com/>
 VACC Camp: <http://www.vaccamp.com/>
 CHAMP Camp: <http://www.champcamp.org>
 Trail's Edge Camp: <http://www.umich.edu/~tecamp/>
 Fresh Air Camp: <http://www.freshaircamp.org/>

The Camp Experience

There are hundreds of wonderful camps out there, and most likely there are several camps for children with disabilities and special needs not too far from most of us. Camp is a fun-filled break that all children deserve to experience. With a little bit of research and prior planning, your child CAN go to camp!