

# Campers with Serious Illnesses

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Camp has long been considered a place for positive youth development. Professionals serving youth with chronic and serious

illnesses have advocated that because of their life situations, these youth can particularly benefit from supported camp experiences (Goodwin & Staples, 2005; Klee, Greenleaf, & Watkins, 1997). The reasoning is that children facing difficult health challenges need a place to “just be a kid,” which involves making new friends, engaging in new and fun activities, all while being medically supported.

“Serious illness” includes both chronic and acute conditions that can cause significant morbidity or be life-threatening. Examples include HIV/AIDS, cancer, hemophilia, and sickle cell disease. Advanced support and accommodation are needed to participate in camp, and medical personnel need to be readily accessible.

Youth with serious illness often face isolation and restrictiveness, have trouble integrating the effects of their disease into their lives, and have difficulty achieving developmental milestones. Serious illness affects relationships with others, such as connecting with peers, figuring out responsibility for care, and disclosing their illnesses to others. Psychosocial factors include stress, fear, shame, frustration, and need for social support, which further interact with uncertainty about the illness’s seriousness and progression. These factors lead to youth with serious illness having a greater likelihood of higher anxiety and violent or sexual victimization; negative body image; lower perceived popularity, self-confidence, self-esteem and self-worth, and distance from peer culture (Miauton et al., 2003).

## Medical Support in Camps

Some people wonder about the ability of youth with serious illness to have a successful camp experience. However, several studies have looked at the medical safety of campers, such as those with HIV/AIDS

(Bergman, Kinsella, Kenny, Barbor, & Zeltzer, 2005) and cancer (Kinsella et al., 2006). These researchers found that campers with these diagnoses were no more likely than other campers to have negative illness-related outcomes because of the camp setting. In fact, participation in camp improved enjoyment and recreational and living skills for over 2,000 youth with a range of disabilities at 15 residential camps (Brannan, Arick, & Fullerton, 1996). Even better, these campers carried their gains in communication, self-esteem, independence, and self-reliance over into their homes and communities.

Camp holds many opportunities for campers to learn different approaches to health care practices. For example, techniques for medication adherence such as pill-taking, scheduling, reminding, and other tasks can be taught to help increase the quality of life for youth with chronic illness (Grey, 1998; Guttman-Bauman, 1998). The five highest-ranked support opportunities at camp were reported by campers to be:

- encouragement and motivational support,
  - modeling,
  - allowing extra time,
  - arranging for peer assistance, and
  - providing physical assistance
- (Brannan, Arick, & Fullerton, 2002)

To provide optimal care for these children, the camp must have a strong medical staff and presence, and an ongoing relationship with local and specialty care clinics or hospitals. The medical staff must include health care providers with expertise in the specific disease groups the camp serves and a strong background in general pediatrics and the common medical issues faced in all youth camps. Staff may include physicians, nurses, mid-level practitioners, and allied health professionals (i.e., dietitians, respiratory therapists, physical therapists). The medical facility must be stocked with medications and supplies needed to provide routine and emergency care for the medical condition the camp is serving.

Relationships with hospitals, clinics, and voluntary health organizations are vital to the success of the camp. In the event a camper has a medical emergency that is beyond the scope of what can be managed at camp, there must be a standing relationship with a medical facility that can provide further evaluation or hospitalization if needed. These medical facilities can also provide information and education to camp staff about the medical condition(s) being served, and are a great resource in finding appropriate and knowledgeable medical and program volunteers. Finally, these facilities are the main source from which parents and children learn about the camping program. These relationships are important in the recruitment of campers to attend the program.

Health care providers must feel confident in the care the children will receive at camp to recommend the camp to their patients. When developing and planning a camp program for children with medical conditions, the medical team must be involved. The medical and program teams work together to develop daily and weekly schedules that are modified to meet the needs of the disease groups they are serving. Disease-specific needs can include daily rest time for children who fatigue easily, adaptive programming for children with physical disabilities, or scheduling times for medications or treatments around meals.

Parents and families must also trust the camp to provide safe and effective medical care and programming to fit the specific needs of their child. When a child is ill, the entire family is affected, including parents and siblings. Open communication with parents before, during, and after the camp experience helps ensure the child's success at camp. To improve the odds that the camper will bring what they learned at camp about living with their illness home to their daily life, the family must also be educated about what the child has learned and how to promote that behavior.

## Research Says

Camps for youth with disabilities and illnesses have received much research attention, yielding an extensive knowledge base of positive outcomes of camp for these groups. Next, we describe a few studies, organized by diagnosis type.

### *Mixed Diagnoses*

- In a study of several similar studies, children showed small, but statistically significant,

improvements in self-perceptions at both post-camp and less so at follow-up. Children with obesity, congenital heart disease, epilepsy, or juvenile rheumatoid arthritis had greater improvements in self-perceptions than children with other conditions. It did not matter if the camp provided an educational component aiming to affect campers' self-perceptions (Odar, Canter, & Roberts, 2013).

- Attitudes toward illness improved after participation in specialty camp programs for youth with epilepsy and asthma (Austin & Huberty, 1993).
- From pre- to post-camp, youth with cancer, kidney disease, and other diseases were more confident in their ability to identify strategies to accomplish goals. Identification and development of personal goals linked to enhancement of perceived health-related quality of life (HRQOL) at post-camp. There were no differences in HRQOL from pre- to post-camp (Woods, Mayes, Bartley, Fedele, & Ryan, 2013).
- For youth with cancer and diabetes, self-esteem and self-efficacy increased, but trait anxiety was mixed from pre- to post-camp (Torok, Kokonyei, Karolyi, Ittzes, & Tomcsanyi, 2006).
- At a camp for youth with cancer, hematological-related illness, renal-related illness, and immunodeficiency-related illness improved in short- and long-term physical symptoms, affect related to physiological hyperarousal and quality of life. In the long-term, self-esteem (in global self-worth) and physical attractiveness improved, but were preceded by adverse effects in the short term. Age, patient/sibling status, and nationality made a difference (Kiernan, Gormley, & MacLachlan, 2004).

### *Cancer*

Research on camps for youth with cancer has shown campers to have:

- Increased social skills (Meltzer & Rourke, 2005)
- Increased self-esteem (Wellisch, Crater, Wiley, Belin, & Weinstein, 2006)
- Increased (a) positive attitudes (sociability, perseverance and confidence, and gratitude and appreciation) and (b) respite (experiencing freedom, and finding a balance between "just being a kid" and managing difficult cancer issues; Gillard & Watts, 2013).
- Differences in perceptions of social support:

- Children's perceptions of cancer-related versus non-cancer-related support came from different sources. Campers did not perceive any differences between support on cancer-related and non-cancer-related issues from parents and people at camp. Classmate and teacher support was different for cancer-related versus non-cancer-related issues for both sets of campers. Oncology campers (but not siblings) perceived close friends as offering different support for cancer-related versus non-cancer-related issues (Wu, Prout, Roberts, Parikshak, & Amylon, 2011).
- Campers found support, understanding, encouragement, acceptance, and education on their disease and treatment through relationships with peers at their camps, but they typically did not experience such support from their healthy friends (Bluebond-Langner et al., 1991).

#### Other Diagnoses

- For youth with neurofibromatosis, there was no evidence that the therapeutic recreation program increased social self-efficacy more than the traditional summer camp program. However, both types of programs did increase social self-efficacy. Campers in the therapeutic recreation program had a greater increase in social performance with peers over the length of the camp session than campers in the traditional camp program (Allsop, Negley, & Sibthorp, 2013).
- For youth with HIV/AIDS, outcomes of camp were (a) forming caring connections (awareness of commonalities, lack of isolation); (b) feeling reprieve and recreation (fun activities, anticipation of and reflection on camp, sense of freedom); and (c) increasing knowledge, attitudes, and skills (conflict management, disclosure, skill learning and education, medication adherence) (Gillard, Witt, & Watts, 2011).
- From pre- to post-camp, youth with pediatric cardiac disease reported decreases in parent anxiety and child trait anxiety, and increases in self-esteem, social, physical, and emotional

functioning (Bultas, Budhathoki, & Balakas, 2013).

- For youth with epilepsy, a significant change in social interaction was observed over 3 years. Despite some decline at the start of camp in consecutive years, the overall trend for return campers suggested a positive cumulative impact of continued camp participation, with improvements in the domains of social interaction, responsibility, and communication (Cushner-Weinstein et al., 2007).

#### Bottom Line

- Understand the illnesses of the campers, especially treatment effects, energy levels, programming adaptations, and psychosocial needs specific to the disease (i.e., presence or absence of support outside of camp, stigma, disease evolution).
- Work in partnership with parents, caregivers, and health care providers for individual camper needs.
- Provide after-camp opportunities for social support to campers, given that they often face isolation.
- Successful coping with the effects of serious illness depends on the availability of contexts that support development. Like all youth, but perhaps to a different degree, youth with serious illness need socialization, recreation, medical support, and opportunities to meet developmental milestones.

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Recommended Citation:

Gillard, A. and Space, S. (2014). *Campers with serious illnesses*. Briefing paper prepared for the American Camp Association.

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