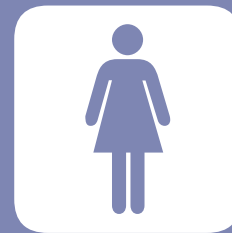


Bowel and Bladder Dysfunction Among Teens



SUPPORT AVAILABLE FOR YOUR STUDENTS

By Vickie Weaver, MSN, COCN, CCRA

Abstract

Adolescence is a stressful time for all children, let alone for those who have additional health needs, especially when that health need centers around something so private as bowel or bladder function. These students tend to feel different, have difficulty making friends and isolate themselves in fear of ridicule or rejection. It is only within the last three decades that continence issues have even been brought to the public's attention, by such people as June Allyson and Florence Henderson. However, these are older women to whom youngsters cannot relate.

During the same 30-year time period, an organization called The United Ostomy Association was becoming visible as a leading support organization for adults who have had bowel or bladder dysfunction and related ostomy surgery. Thankfully, 25 years ago, two nurses, one who had a daughter with an ostomy, approached this organization to begin a program to meet the needs of teens. The teen support network has grown into an annual UOA Youth Rally and a national support network with a website, discussion board and mentoring program, all supervised by volunteer adults. The adults are either WOC Nurses (Wound, Ostomy and Continence), or adults who are members of UOA who have had an ostomy or have a child with an ostomy. The information presented in this article is intended to provide school nurses with a resource they may utilize while coordinating care for their students who have bowel and/or bladder dysfunction.

The United Ostomy Association Annual Youth Rally

"Living Independently For Tomorrow, You Are Not Alone". Eight powerful words that were adopted as the overall theme of the UOA Youth Rally about 20 years ago carry a stronger meaning each year, after each rally is over. The rally is a 5-day program held every July for youth aged 11 to 17 who have bowel and/or bladder dysfunction. It is held on a college campus where dormitory facilities, meals and off-campus transportation are readily available.

Many of the youth who attend the rally have never encountered anyone else with an ostomy or bowel/bladder dysfunction. Adolescence *without* a medical problem is a tough time in a child's life. Common emotional reactions of adolescents with a bowel or bladder dysfunction are social isolation, fear, and low self-esteem. With that in mind, it is the objective of the rally staff to provide education, networking and support for these children and allow them to begin to build positive behaviors and thought patterns that will continue throughout their life — a difficult challenge in five short days.

The educational sessions provided are nontraditional. To hold the youth's attention and make the experience more positive, most of the classes being taught (such as anatomy of the gastrointestinal or urinary systems) are presented in the game-show fashion. We have experienced "Ostomy Jeopardy" and "The Strongest Link," for example. Post-rally evaluations have all been favorable; the game-show style helped participants remember the information, which

was understood much more clearly than in a classroom lecture setting.

The youth also enjoy outings, such as a trip to an amusement park, an endurance challenge such as canoeing, or a ropes course that includes levels for all participants (including our physically disabled youth in wheelchairs), and shopping. However, the most beneficial part of the program for youth is the opportunity to meet and network with other teens of their own age and diagnosis from across the country. There are both scheduled and spontaneous "rap sessions" that take place in which one can almost see transformation in children by changes in their expression, body language and interactions with others.

One young man, Eric, who had Vater's syndrome, attended the rally for years. During his first year, the counselors were frustrated, because Eric was so quiet and isolated himself from all the others in the group. He attended all the functions, but would stand under a tree or behind the group, alone. Occasionally, he would speak to a counselor when one would join him in his solitude, but his head would remain lowered. All of the staff believed Eric would not return, and that his experience was not positive; but Eric returned a second year, and the tree he would stand under was not as far away from the group as the previous year. He would continue conversations with the counselors when they spoke to him, and his head was not bent as far to the ground. Subtle differences, but the staff noticed. The changes continued each year, and by the time Eric was 17, his last year to

attend, he played the piano at the rally “graduation ceremony,” was smiling and interacting with the other teens in his group. Eric is now 20, and in college. The staff has asked him on occasion to speak with another teen who has Vater’s syndrome to offer encouragement and support, and Eric willingly offers himself for whatever he can give. That is what the UOA Youth Rally is all about!

Each year, to evaluate the effectiveness of the rally, we have the youth fill out pre- and post-rally questionnaires asking what their expectations for the week are, and if they have been met. A summary of responses to the question from last year “What did you learn at this rally?” follows.

- “I learned more about myself and others than I ever thought possible”
- “Whatever the situation, it’s how you handle it that makes the situation good or bad”
- “More independence”
- “It doesn’t matter what’s on the outside, but what’s on the inside”
- “It’s ok to be different”
- “I’m secure with my ostomy now”
- “Better techniques to take care of myself”

Attendees of the rally have come from all across the United States, including Hawaii and Alaska, and several have come from Canada. The requirements for a youth to attend are age from 11 to 17 and signed consent from parent or guardian. A physician must provide health certification and approval for the youth to attend and participate in activities. The fee is currently \$350 plus airline transportation. Most of the children need to seek sponsorships of some kind from local UOA chapters, WOC Nursing affiliates and civic organizations. The staff is all volunteer as well, and are required to find their own funding. Many of them are actively involved in seeking out funding for the youth.

One of the greatest challenges has been in reaching across the country to find the youth. It is our dream that by reaching out to your professional group we may achieve the goal of reaching farther into the need and touching the lives of those who might not have known about this special group of children.

The last day of the rally, when all are boarding the airplanes for the flight home, there’s not a dry eye to be found among the youth or the staff. The most common

response one can hear is that the children have touched the life of the staff and each other in such a way that no one will ever be the same.

As school nurses, you are challenged with the safety and well-being of these youth for 10 months of the year and a minimum of 5 hours a day. It is our hope that the resources listed within this article will be of help as you are developing your plan of care for each child who has a bowel or bladder dysfunction. Help and support are always available — and you do make a real difference in the lives of these children. 🍷

RESOURCE

United Ostomy Association
19772 MacArthur Boulevard, Suite 200
Irvine, CA 92612-2405
(800) 826-0826
www.uoa.org

This web site contains a list of publications and educational brochures that are available. It also has a teen network message board and information on the teen-mentoring program. The Youth Rally program information, application and photo gallery have a special section of their own.

ABOUT THE AUTHOR

Vickie Weaver, MSN, COCN, CCRA is a Certified Ostomy Care Nurse and Certified Clinical Research Associate. She has been a member of the United Ostomy Association and Youth Rally Medical Chairman for the past 3 years.

