

Disabilities Awareness

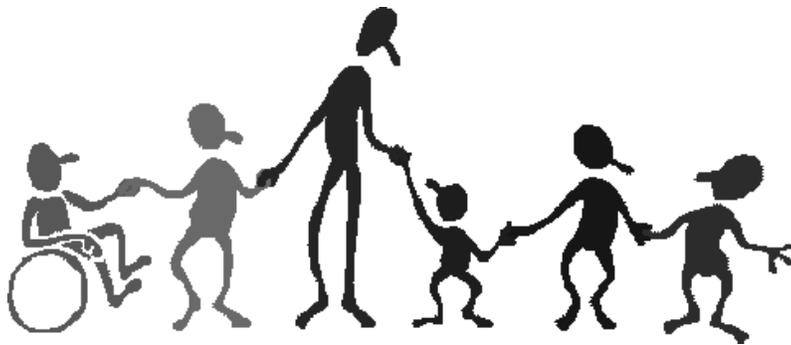
A special issue prepared by and for high school students

SUMMER 1999 EDITION

DISABILITIES AWARENESS IN MY LIFE

by Colin Harte, Guilderland High School

Disabilities Awareness has played an important role in my life. My present interest in it grew out of my early involvement as a child. In elementary school I was given the chance to serve as a student judge for disabilities awareness art contests sponsored by the NYS Commission on Quality of Care. Children from schools all across New York State were asked to send in drawings to express their personal message of equality and acceptance of people with disabilities. It was frightening to see how many drawings inadvertently depicted a negative message instead of the positive one called for by the contest guidelines. Later I experienced the same feeling when I judged a disabilities awareness writing contest and read many of the entries submitted by middle school students.



After seeing so many negative representations of people with disabilities, I decided I wanted to do something to help change the common misconceptions the general public had. I started to take notice of the challenges that people with disabilities faced every day. Some of them were concrete problems like the inaccessibility of buildings and the lack of accessible public

transportation. I began to notice where people with disabilities couldn't go. I began to see that some of the worst challenges they faced, however, were attitude problems like the endless teasing or using the names of different disabilities as insults. I began to notice how people communicated (or failed to communicate) with disabled people. I observed that people thought someone with a disability was only a disability, therefore less human, and inferior to us. Expectations were low for them and they were more often sitting alone in a school cafeteria or not included in social events after school. I hoped that my involvement in a New York State publication like the Disabilities Awareness Newsletter would help correct some of the misconceptions and lack of information I observed in my own world. I began to write articles that centered around positive accomplishments achieved by active members of our community who happen to have a disability. I continued with the Newsletter for three years and finally became its editor. During this past year I helped establish a New York City editorial board to complement our upstate board.

Next year I will be a freshman at Bard College and I plan to continue my involvement with disabilities awareness by organizing activities in the local elementary schools surrounding the college. I have received a Leadership Grant from Bard to help finance this effort. My participation in disabilities awareness programs at the Commission has taught me that it is possible to help people change their attitudes.

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Losing Sight

by Nathaniel Lewis, Albany High School

Twelve years ago, at the birthday party of a friend, was the first time I met somebody my own age who had a disability. He was tall for his age, thin, and wore eyeglasses, just like I did. It was this commonality that initially attracted me to him, since I didn't know very many kindergartners who wore glasses. I had begun wearing glasses to correct a case of strabismus at age two, and was able to see perfectly when I put them on. However, I was not aware of the fact that his glasses did very little to sharpen his vision, and that he was legally blind.

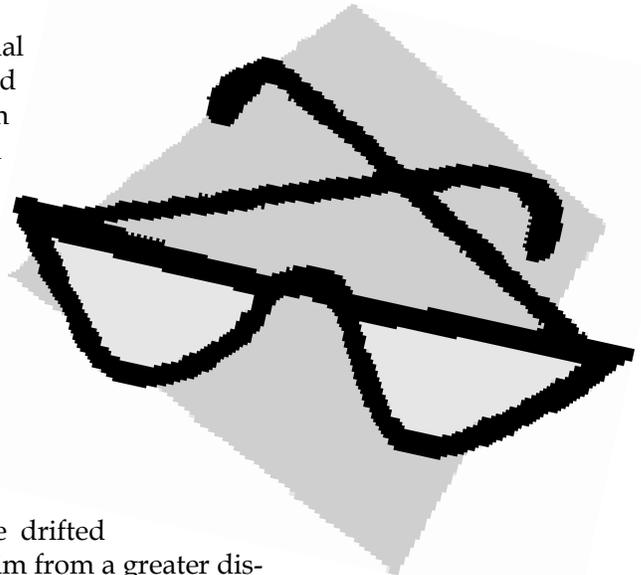
On the last day of second grade, at the unofficial annual picnic at Westland Hills Park, we became good friends. As we moved from the swings to the jungle gym to the sprinklers, I realized how much we truly had in common. We enjoyed the same things: Legos, swimming and being Cub Scouts. Throughout third grade, we spent nearly every weekend together. During this time, though I had been informed of his disability, I never made any differentiation between his abilities or personality and my own. Although I often helped to direct him when he didn't seem to quite have his bearings, I never doubted that his capabilities were similar to my own.

After that year, we were not assigned the same teachers for fourth grade, and unfortunately, we drifted apart. As we finished elementary school and I watched him from a greater distance, his disability somehow became more apparent to me. When other kids asked me if I knew him, I would think of him as the boy who couldn't see well, or the one in the class who had to read large-type books. Why was I doing this? In part, it may have been because I was forced to look at his situation with less subjectivity. Perhaps it was because I began to recognize there were a few things he couldn't do as well as others. Most of all, I believe that my feelings came from the fact that society emphasizes disabilities as a difference between human beings.

While it is necessary to be aware of other's disabilities, they should not be the distinguishing factor between two people. As we continued through middle school, I realized that losing contact often causes one to lose sight of somebody's true personality, and the characteristics that make them who they are. However, I would eventually notice his maturity, perseverance and determination in all areas of his life, qualities which have led him to develop into a young man I truly admire.

During my junior year, we were placed in the same Aquatics class. I discovered our interests now differed, but that we had both pursued and achieved a number of personal goals. The last time we spoke, at his parents' New Year's party, I was inspired by the amount of things he had accomplished in the past year. He had become manager of the school store and had won Albany High School's only gold medal in the regional DECA business competition. He got a job at Eastern Mountain Sports. Over the summer, he had participated in a rigorous mountain climbing and hiking trip in the Adirondacks, not for a second letting his disability get in the way of doing something he loved.

I thought back to that first day at the park, when I had worried that his sight might cause him to fall and hurt himself. Now, he had pushed himself to do something considered difficult for anybody. This inspirational individual has never allowed his disability to become his most prominent quality, and consequently, he has encouraged me to view disabilities in the same way. I feel that he has served as an example to society, showing that disabilities do not dictate an individual's personality or quality of life.



What To Do With A Million Dollars

by Emilie Higgins, Holy Names Academy

If I were ever asked when I was younger what I would do if I inherited a million dollars, my answer would always include buying all of the toys I could ever imagine or a mansion or other luxuries that I could only dream about. Now my answer would be different because of a situation that has brought a significant challenge to my life. My mother was diagnosed with MS when I was born. It progressively took over her life and our family life.

Each day was, and still is, a hard, frustrating and stressful time. This incurable disease has had a dramatic effect over the years starting when I was in kindergarten. I remember when my mother started using a cane so she wouldn't fall when she walked. She could still work, drive, and go on outings with me, her only daughter. In the beginning I didn't know how to grasp it all but I gradually understood a little more each day.

By the time I was in second grade my mother needed a walker. Because I loved my mother who was my best friend, I hated to see what MS did to her. I still do. It eats me up inside when I think about how the disease is getting worse and worse. I sometimes tell myself that this is as bad as it can get; but I have been wrong about that.

By the time I had entered middle school she was in a wheelchair. She was no longer able to do her favorite things - work, drive or swim. I wondered why there wasn't a cure for her. Is it because there is not enough money for research? I think every day that this will be over soon and there will be a new medicine she can try. There have been many drugs that doctors have prescribed but none seemed to work. My mother and our whole family get our hopes up so high every time. Nothing seems to stop the progression of this disease.

MS has taken away a perfect life and for no reason. When something hurts this much you try to fix it or find a way to make it better. That is why if someone asked me what I would do with a million dollars, I could think of no better way to spend it than on research in MS. Then maybe the hurt would go away from my mother's life and from all the people and families who live with this awful disease.

Understanding Me!

by Saugerties High School Students

Super

In Special Ed teachers understand me.<

People

It's a good place to be.

Educating

My friends and I have opportunities.

Considerate

It's a fun place to be.

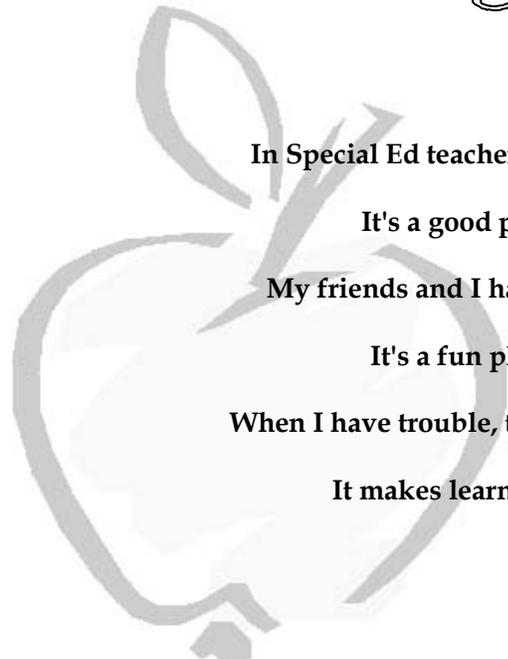
Individuals

When I have trouble, teachers help me see.

About

It makes learning carefree!

Life

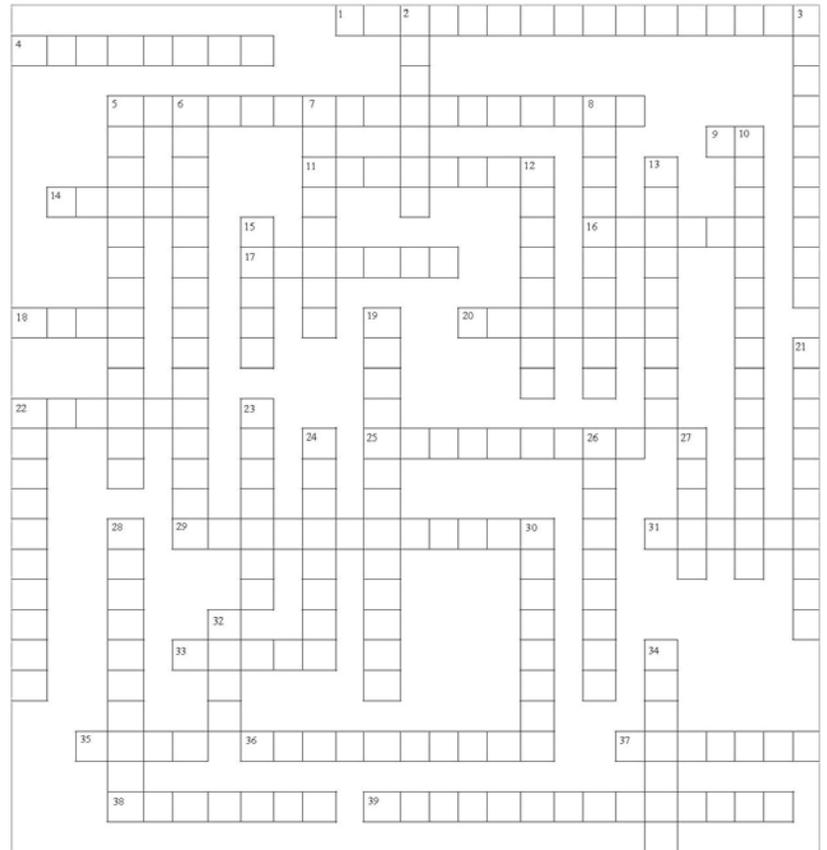


Disabilities Awareness Crossword Puzzle

by Rebecca Lozman and Jessica Murphy

ACROSS

1. Characteristic behaviors of this diagnosis include unwillingness to accept responsibility, tendency to act impulsively, unstable personal relationships, impatience, and recklessness (pl.).
4. The influence others can place on you that can interfere with your judgments.
5. A chronic condition marked by progressive wasting away of muscles.
9. A condition caused by damage to the motor centers of the brain, sometimes as a result of an inadequate supply of oxygen
11. An eating disorder.
14. A sudden attack of unreasonable, overpowering fear.
16. A fear of a particular object or situation.
17. The act of ending one's own life.
18. For many disorders, there are treatments but no known _____.
20. A system of raised dots enabling people who are blind to read.
22. A condition with childhood onset which impairs the ability to communicate and interact with others.
25. Depression may be caused by a deficiency of this chemical.
29. A system of communicating with the hands.
31. Strain or pressure.
33. A source of much misinformation about disabilities.
35. Those who do not have the ability to perceive auditory images are _____.
36. A sleep disorder which makes a person fall asleep without warning.
37. Another name for manic depression.
38. A sign of change in a body's function or appearance due to a disease or disorder.
39. Adjustments.



DOWN

2. The Commission on Quality of Care in this state funds the Disabilities Awareness Newsletter.
3. Respect and belief in yourself which enhances mental health.
5. The placement of students with disabilities in classroom with their non-disabled peers.
6. A sporting event for people with disabilities.
7. Having the ability to adjust.
8. An inherited condition in which a person's blood lacks the ability to clot.
10. Olympic level competition for athletes with disabilities held on the site of the Summer Olympics.
12. This newsletter is a form of _____ or speech/actions to improve the lives of people with disabilities.
13. Mental retardation means ____ to ____.
15. A volleyball team for people with disabilities (abbr.).
19. A genetic disorder (two words).

Crossword (continued from previous page)

21. People with disabilities and people who are not disabled can share this.
23. In its extreme form, one of the first warning signs of depression.
22. An addictive disorder by excessive imbibing.
24. Severe failure to learn reading not explainable by lack of experience or sensory impairment.
26. Involving everyone in the things you do - choosing your companions without regard to race, religion, or ability.
27. The 1999 editor of the Disabilities Awareness Newsletter.
28. A progressive condition that slowly kills nerve cells in the brain.
30. A neurological condition characterized by seizures which happen when the electrical system of the brain malfunctions.
32. An uneasy feeling, awareness of foreboding danger.
34. Painful uneasiness of mind over an impending event.

Solution on page 7

Think About Thin

by Sara Pawlowski, Averill Park High School

"From now on you will eat what I tell you to this is the last time you'll refuse to eat. From now on..."

...Be pretty, but beauty is only skin deep

....Be sexy, but not sexually active

...Be happy, but please others, first and foremost

....Be thin, but stay healthy

....Be thin

....Be thin.



It sunk in. We received the message. Like everything else, it sunk in. It sunk in with magazine covers and standards and scales and diets. It sunk into the minds of seventy percent of the young women between the ages of 14 and 24 and how many can wiggle free from it? Maybe you were someone who thought the "Am I fat?" question and answer period was unique to you? Unless I have my facts wrong, if we don't eat, we die. Even with that common knowledge, there are still people who don't eat. Those people will die. It is the reality of an eating disorder. Blame the media or the culture or the "distorted society" in which we live. It's the models. It's the parents. It's the kid who called you obese when you were five.

We all wonder who is leading the revolution that is wasting people away. Let us worry more for the ones who follow. The question should not be why anorexia and bulimia start, but why they don't stop. Anorexia and bulimia are the biological diseases that mirror the "distortion of a natural human response to famine."

Psychologists, social scientists, historians, and physicians seek to explain the contemporary causes of eating disorders. We have statistics and case studies. We focus on the root of the problem. We examine whether the instinct to control has gone awry or the problem of low self-esteem has made a permanent mark. We want there to be one tidy packaged reason. There is not one reason. There are many. Each individual is different. Each individual has a separate obsession.

If you actually sit and observe real Americans - passing by, walking along, living their lives - how many of them are perfect? There are only ten super models for every thirty million people in this country. Only ten. Look and arrive at the realization yourself.

WHAT MY FATHER'S LIFE HAS TAUGHT ME

by Dawn Peoples, Cortland Christian Academy

My father has a rare autoimmune neuromuscular disease which is similar to Lou Gehrig's disease (ALS). He had been having some muscular problems on and off for several years. He began losing strength in his legs and, to a lesser degree, in his arms. My Dad worked in a hospital intensive care unit and was on the go a lot at work. Suddenly, in October 1995, he had to stop working. After seeing several different doctors in different cities and having what seemed to be a zillion different tests, the auto-immune diagnosis was reached.

We knew that Dad had some medical problems but we had always been told that they were not debilitating. When he had to stop working, it was a real jolt to all of us. My Mom told us that Dad had worked since he was fifteen years old. He even worked full time while he was in Bible School in 1986. He was stopped in his tracks by the diagnosis when he had just begun taking courses at Syracuse University.

My Dad still keeps going and does as much as he can. Sometimes I think he does too much and sometimes I think he gets stubborn when he is told to slow down or to rest. Even though he is classified as "disabled," he tries to keep that label from complicating his life. He views himself as still being able to do things - just in a manner that might be different from how most people might do the same task.

When he had to stop working and then received the auto-immune diagnosis, it was pretty hard to accept. My Dad had always been pretty active and now he had to cope with a condition that will one day overcome him. For the first year or so, my Mom and I slept very little because we were afraid that Dad would stop breathing while he was asleep, and die. Whenever he wanted to do something, I thought that he might need help and I was always right there for him. I have since learned that

Dad can still do many things by himself. I don't think that Dad has really learned his limitations yet but Mom and I are there to help him. Dad can't be left alone because he has some problems with his balance at times. He knows that he shouldn't be alone yet once in a while he wants to be. Learning when to help and when not to help is an important part of living with someone who has a disability.

I had the opportunity to go with my parents to several of the doctor appointments. I saw how they examined him and tested him. I saw doctors testing his muscles and nerves by shocking him with electricity and sticking needles into his arms and legs. He had four muscle biopsies so that the doctors could examine his muscle tissue directly. There were many times that I felt as if I knew more than the doctors did because I live with my Dad and they don't. I saw firsthand how he had to slow down and how he had been limited in his activities. They only see him for a few minutes now and again and think they really know what he is going through. They don't.

While we still aren't comfortable with the diagnosis

and the prospect of things to come, we have learned several things over the past few years. First and foremost is that we are not in control of everything even though we would like to think that we are. Even though it is hard to imagine, I believe God has a reason and a purpose for my Dad to go through this. We also know that physicians are not always what they seem to be. We expect them to have all of the answers but they are only human like us. Dad's goal is to be as active and independent for as long as he can. We don't try to do everything for him now and we don't panic every time he has a problem swallowing or with his balance. My father's life has taught me to accept what I cannot control and to have faith that things are as they should be.



Remaining Normal

by Robert Mulligan, Albany High School

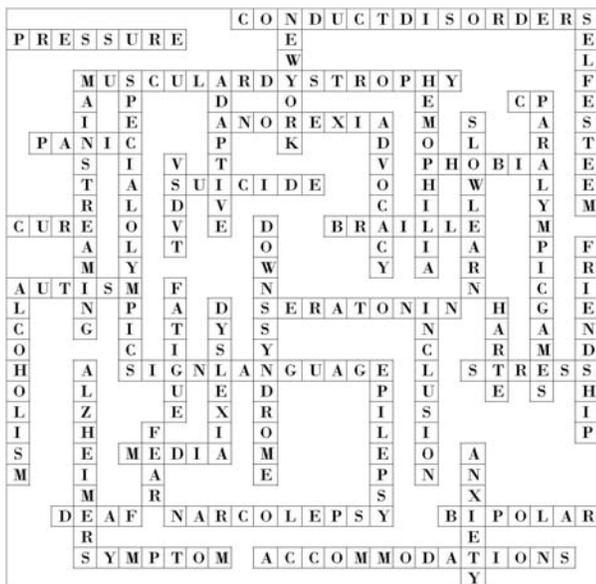
Ankylosing Spondylitis. When I first heard these words, I was tempted to say "God bless you," because I had never heard of such a disease. I could not appreciate that I would be living with it for the rest of my life. Ankylosing Spondylitis (AS) is a form of arthritis that affects the peripheral joints of the body, including the spine, bowels, and even the eyes (iritis). It causes the joints and ligaments that allow the back to move to become inflamed. It often begins in the late teens or early 20's and if it is not treated correctly, it can cause the spine, hips, and ribs to become rigid, which will make bending, turning, flexing, and breathing difficult. The actual severity of these symptoms vary a great deal from person to person. An early diagnosis along with proper treatment can help pain and stiffness be controlled and reduce or stop major deformity. It is important for all those afflicted with this disease, their families, and their friends, to fully understand the causes and effects of this arthritis and the ways to manage it throughout life.



The exact cause of AS is still unknown. Over 90 percent of people with AS possess a genetic marker called BLA-B27. This gene is involved in the body's defense against infection. It has been confirmed that other genes are involved in this disease as well, but they have yet to be identified. A person can have this gene and not have AS. There also exists an environmental factor in the onset of AS. It appears to be normal bacteria in the bowel.

I was diagnosed with AS after several occurrences. I suffered a head injury during a wrestling match. My skull was cracked and I was put on an antibiotic to fight off any possible infection. This drug caused my bowels to become infected by another disease called C-Difficile bacteria. After that was cured, I became afflicted with a Septic Hip. My hip was filled with infectious fluid. During this time I developed iritis, an inflammation of the eye. I had suffered iritis before. To make sure the infections would not come back, I had to stay on a home IV for six weeks. I was also identified as a carrier of the gene BLA-B27. During this time my doctors simply put the pieces together.

Crossword Solution



Before I was diagnosed with AS, I had never heard of it. Even though it shares many bonds with other popular ailments, it is not widely known. Organizations such as The Arthritis Foundation offer it attention in its bimonthly magazine Arthritis Tot*. But it is not as popular or as widely diagnosed as afflictions such as Rheumatoid Arthritis, Osteoporosis, and JRA.

The Spondylitis Association of America (SAA) informs people about Ankylosing Spondylitis and its related diseases and promotes education, research and mutual support. The Association publishes a quarterly newsletter titled Spondylitis Plus. The SAA, along with the University of Texas-Houston have established the North American Spondylitis Consortium (NASC). The NASC is composed of nine prominent medical institutions spread across the country that will work with each other to help find a cure for AS. The SAA is also the creator of The Quest for the Cure, an organization dedicated to raising

Remaining Normal continued on next page

Remaining Normal (continued from previous page)

money for AS research. The National Spokesman for the SAA is the first baseman for the Philadelphia Phillies, Rico Brogna. He is a prime example of how a body operates if the disease is properly treated and managed.

The proper treatment and management of AS is a regiment of exercises that concentrate on the back and pelvic area. These numerous exercises can be obtained from any Rheumatologist, the Internet, or a Physical Therapist. Even more important is the maintenance of perfect posture. Someone with AS should remember to always sit up straight. Exercises that keep the back and neck strong will also help maintain good posture. Breathing exercises and aerobics can help keep the chest and ribs flexible. Sports such as Swimming and Volleyball are also helpful because they stretch out the muscles in the body and are lower impact forms of activity. Swimming also helps the spine, neck, shoulders, hips, and breathing. Medication is an important part of treatment. Nonsteroidal anti-inflammatory drugs (NSAIDS) usually reduce inflammation and pain. It is important to talk with your doctor about which drugs are for you.

Maintaining as normal a life as much as possible and remaining active as possible without overdoing it are essential. I am not allowed to participate in high impact sports anymore, but I plan to be on the outdoor track team this year. I also walk, play baseball with my brothers, lift weights, and stretch every single day. The most important thing to do is not to let AS dominate your life because there is so much more out there.

**Websites where you can
learn more about
Ankylosing Spondylitis:**

Spondylitis Association of America (SAA)
email: spondy@aol.com
<http://www.spondylitis.org/>

National Ankylosing Spondylitis Society
(NASS)
email: nass@nass.co.uk
<http://www.nass.co.uk/>

Arthritis Foundation
<http://www.arthritis.org/>

Depression to Death

by Satarra Alexander, Redemption Christian Academy

Caught up in fear, hiding behind shame
For people to see me, for them to call my name.
Nowhere to run, I wish I could go.
How am I going to make it? I really don't know.
I feel extremely lost and so all alone
Like I'm wandering around with no place to roam.
Trapped behind my fears, lost in my hate
I'm screaming real loud but no one can hear.
I'm locked behind a wall that is no longer sheer.
I can't see beyond the cries of my empty heart.
I have no more self-confidence and my life's falling apart.
Life can be a labyrinth that's endless in its paths.
I'm hurt. I'm lost. I'm subdued within the wrath.
I can't hold on. I'm going to fall.
I just want to be free from my stress and all.
All of my fear and low self-esteem
Where life is much worse than it really seems.
Anyone hear me? I'm calling out of distress.
Please hear my cries. Feel my pain. I'm depressed.
I have lingered on far away for too long with no friend.
If help doesn't come soon, my life will end.

THE FEAR OF LIVING

by Allison Sheedy, Shenendehowa HS

Have you ever felt depressed, confused or stressed? Of course you have. We all have.

Learning to conquer feelings like disappointment and self-doubt is part of growing up. For some teens, however, these feelings become overwhelming and their thoughts turn to suicide. Today suicide ranks as the third leading cause of death among 15-24 year olds, falling short only of accidents and homicide. According to the American Association of Suicidology, the teen suicide rate has skyrocketed 200 percent since the late 1950's. Despite these alarming statistics, I know what you must be thinking, how can this be? Most of us don't know someone personally who has committed suicide. This is true. Completed teen suicides are rare although more teens are killing themselves today than four decades ago.

Why? is a question commonly asked after a teen commits or attempts suicide. Why would a youth want to take his or her own life? Psychiatrists, psychologists and public policy advocates have conducted many studies in hope of seeking the answer to this question that remains, even today, as complex as youth themselves.

It comes as no surprise that hopelessness and depression top the list of links to teen suicide. Alcoholism and drug abuse also play a huge part, as does a history of physical or sexual abuse. In addition, divorce, problems at home or at school can contribute to a teen's choice to die.

Many of the symptoms of suicide are similar to those of depression. Help should be sought for teens who display one or more of these signs. They include:

- ◆ Change in eating and sleeping habits.
- ◆ Withdrawal from friends, family and regular activities.
- ◆ Violent actions, rebellious behavior or running away.
- ◆ Drug and alcohol abuse.
- ◆ Neglect of personal appearance.
- ◆ Marked personality change.
- ◆ Persistent boredom and decline in quality of schoolwork.
- ◆ Frequent complaints of physical symptoms, often related to emotions, such as headaches, stomachaches, and fatigue.
- ◆ Intolerance of praise or rewards.

The most important thing anyone can do for the affected person is to help get appropriate diagnosis and treatment. This may involve offering emotional support and encouraging the individual to stay with treatment until symptoms begin to abate, which is usually several weeks. With support from family, friends and medical professionals, serious problems can be prevented and affected teens can begin to heal and return to a

healthier path of life.

People almost always feel uncomfortable talking about death, but if a child or adolescent says, I want to kill myself or I'm going to commit suicide, do not take it lightly. Immediately seek professional help. Support and even just a chance to talk can be extremely helpful. As T. Michael Anthony, the executive director of the National Suicide Help Center states, "Suicide is not so much the desire to die as the fear of living." Maybe you can help alleviate someone's fear.



ASK US

by Frances Ford and Jessica Murphy, St. Thomas School

Dear F & J,

I'm worried about my cousin. He's always feeling down and never smiles anymore. I fear he may be suffering from a case of depression, but he's always been such a happy person. What could have caused this disorder and what are the symptoms?

-Sincerely, Nicholas

Dear Nick,

We suggest that you talk to your parents and then to your cousin's parents and express your concerns. They may be able to help you better understand the situation. Signs of depression include: continual sadness or anxiety, lack of interest in normal activities, unusual weight changes, and peculiar eating or sleeping habits. Continual thoughts of mortality, guilt or worthlessness are also symptoms. But remember these symptoms have to be in place for a significant period of time. Everyone has an occasional down day and it is normal to be depressed over an important loss or some other sad event in your life.

If he is indeed suffering from depression the cause could be a number of different things. No one is 100% sure what causes mental illness. Some believe that depression can occur due to a deficiency in the brain chemicals serotonin and norepinephrine. Has anyone else in his family ever been diagnosed with depression? If so, the cause may be genetic. Be careful not to place blame on anyone for what is happening to your cousin. It won't help the situation. Also, certain personalities characterized by low esteem and extreme sensitivity to stress can be more susceptible to the disorder.

It doesn't really matter why this is happening to your cousin, does it? What matters is that you care about him and want to help. Your cousin may seek help from a counselor. Offer your support if he does and let him know that you are there for him.

Dear F & J,

Every day my life seems to get worse and worse. It is getting to the point where everyone seems to hate me and everything I do ends in failure. I sometimes think that ending my life now would be so much easier. It fills my thoughts more and more each day. I know these ideas are unhealthy, but I don't know who to turn to for help. My parents are so busy and I don't want to worry them even more, besides they'd probably just yell at me. I don't know what to do so please give me some ideas.

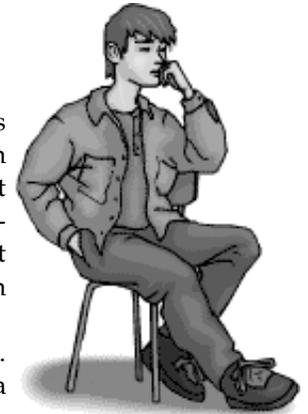
-Anonymous

Dear Anonymous,

First of all your parents love you and would want to help in any way, shape, or form. Remember that suicide is a permanent solution to what may only be a temporary problem. I can tell you without a doubt that you would not be bothering your parents to talk with them about your feelings. They will want to guide you through these difficult times. Do not be afraid to ask them or another adult you trust (such as a special relative, teacher, friend or mentor) for some help.

In addition there are many local agencies such as the American Psychiatric Association who can refer you to a professional in the mental health field. Try also contacting your family doctor, local crisis center, a clinic, or a family service agency. Check the yellow pages under Mental Health Services for other sources.

Just remember there are people out there who want to help you. We know it may be very difficult to imagine that other people could understand and aid you, but it is true. It is good that you recognize these thoughts as unhealthy and want to seek help. You've already taken the first steps on the road to an improved healthy life-style. We encourage you to take the next step and talk to someone.



Ask Us continued on next page

Ask Us (continued from previous page)

Dear F & J,

A new student came into our school. She uses a wheelchair. I wanted to help her out and make friends, yet all my friends say that there's no use and nothing I can do. I know that this is untrue and I want to make others aware of the fact that people with disabilities are equals and that we can help them just as they can find ways to help us. What should I do?

-Lucinda C.

Dear Lucinda,

We are so happy that there are people like you who realize this and want to help all people to live in harmony together. It is true that all people may not seem equal, we are all similar in some basic ways. People with disabilities sometimes need help, but so do we! A person in a wheelchair may need your help but you may need her's as well.

To help raise awareness of this you might try inviting the girl to participate in activities with you and your friends. Make sure that the locations are accessible and the activities appropriate for her condition. Others will see she is more like themselves than they had thought.

We have some other ideas for you if you want to get on the disabilities awareness bandwagon. Speak up when people say unkind things or use inappropriate language referring to those who are disabled. Write letters of thanks to TV shows or movies when they portray characters with disabilities and encourage other forms of media to do the same. Talk to younger children about people with disabilities and encourage them to openly discuss their questions and concerns. Also recommend that others read this newsletter which will help them to see that we are all equal, to understand different disorders and diseases and to know that there's more than dis- to disability.

Dear F & J,

Recently my sister was in a car accident in which she fell asleep behind the wheel. Afterwards she visited many doctors. No one would tell me anything, but I did overhear that she was diagnosed with a disorder called Narcolepsy. I was wondering what you could tell me about it?

-From a worried Bro.



Dear Worried Bro,

Narcolepsy is a sleep disorder in which a person falls asleep without warning. As you must realize from your sister's accident, this can be very dangerous if untreated. Take heart, now that your sister has been diagnosed there are many treatment options available to her from therapies to medications.

We know it must be frustrating when no one will talk to you. Your parents probably didn't want to scare you. In the future try sitting down with them and openly discussing your questions. Assure them that you would rather have them explain things fully than hide the truth in order to protect you. They may respond better to this technique knowing that you can handle such information responsibly.

Dear F & J,

Recently my father became paralyzed from the waist down in a riding accident. He now uses a wheelchair. I'm afraid to talk to him, fearing that I will say or do the wrong thing. Please give me some advice.

-Thanks, Parker

Dear Parker,

Don't be afraid to talk to your father. We're sure he would want you to talk openly instead of ignoring him or imagining things as much worse than they actually are. Speak directly to him and make eye contact, don't stare at your feet or mumble, this would obviously make him much more uncomfortable. Stand or sit at a reasonable distance, as you would with anyone else. Don't be afraid of offending him by your usual slang (gotta run or jump on in there).

Be yourself, he will respect that and feel more relaxed in your company. Just remember one important fact: your dad is the same guy in or out of the wheelchair. He loves you and wants you to feel as though you can always talk to him, about ANYTHING!

Special Accommodation: Some Practical Advice for Students

by Justin Leader, Pearl River High School

This May, I took an Advanced Placement (AP) Examination in European History and several SAT II: Achievement/Subject tests. My first experience with these advanced tests has given me a new perspective on special accommodations for students with disabilities taking these exams.

Students who want to demonstrate their proficiency on standardized tests face many obstacles. Their performance on critical examinations such as the SAT I and II, the Advanced Placement Exams, and Regents Exams can be severely limited by disabilities when they do not receive the proper exam accommodations. On these exams, as well as in-school exams, students with disabilities are entitled to certain special accommodations according to the type and extent of their disabilities.

For visual and hearing impairments, there are a variety of accommodations that can include different test materials, such as brailled or large print test booklets and written instructions for all parts of the examination. For orthopedic impairments, there must be test and toilet facilities accessible to persons with mobility disabilities. For learning disabilities and mental health impairments, accommodations include extended time, separate settings, a reading/writing proctor, a recording device, and a word processor. These are just a few of the examples of accommodations available to students with these and other disabilities.

I have Attention Deficit Hyperactivity Disorder (ADHD), so my accommodations include extended time, a separate and quiet setting, and a word processor. When I took the AP European History Examination in May, there were many complications. Although the accommodations I needed were designated in my Individual Education Plan (IEP), the process by which these accommodations would be implemented was not explicitly detailed and this led to serious problems.

A lack of communication and a failure to decide who would be responsible for such basic

requirements as setting the time, location and arranging for use of a computer for the test, made a difficult testing situation even more so. A delay in starting the test by almost an hour while school staff tried to figure out logistical details caused me an enormous amount of anxiety.

Unfortunately the late start proved to be a major problem. Even though school personnel had indicated to me in a meeting held earlier in the week that they would start the test early so that I could conclude it at the same time as the rest of my classmates (approximately 4:30), this did not happen. The timing was especially important to me because I needed to be at the premiere of a musical I was performing in, which started at five o'clock. I wanted to keep my word to my fellow thespians and be there on time. Because of the delay caused by poor planning on the school's part, I was forced to stop in the middle of one of the required essays and leave the test unfinished. I have not yet received my grade, but undoubtedly it will not represent the year of hard work and effort that I put in to a college-level course.

It is clear to me through this unfortunate experience that establishing an understanding with school personnel about required accommodations is only half the battle. Students must also make sure that the school will be able to properly implement those accommodations. In my case, they were not. That means that, out of necessity, students with disabilities must become their own advocates. They must be proactive in establishing the manner and method by which the testing accommodations will be implemented.

For more information on testing accommodations, contact the New York State (or your respective state department) Educational Department of Vocational and Educational Services for Individuals with Disabilities (VESID). I have found very useful their "Test Access and Modification for Individuals with Disabilities" booklet.



Disabilities Awareness and Art

by Robert McHugh, Shaker High School

You don't have to work too hard to find places where your awareness of disabilities helps you see things clearly and understand more about your own world. I'm interested in art and I'm working at the Hyde Museum in Glens Falls this summer. I'm helping develop an education program that will interest younger kids in the museum's collection. I have been looking everywhere to find out how to get kids to look at paintings that otherwise might not interest them at all.

I saw something on the Internet which I thought would give me some ideas. It is a website created by Tom March called "2 Views 4 U." He uses



Edvard Much, *The Scream*

questions to get the viewer to compare sets of interestingly matched paintings. I especially liked his combination of "The Scream" by Edvard Munch and Van Gogh's "Corridor in the Asylum."

March tries to get the viewer to define mental illness by comparing the two painters' interpretations of it. He starts out by asking us to think about the two titles of the paintings and he draws us into examining how each of the painters uses repetitions, shapes, lines, color, and patterns to represent his view of mental illness. I think he does something positive for art and disability by insisting that we look for "cool things" that attract us to each painting.

March asks us if it is more disturbing for us to see a person who is mentally ill or to see through the eyes of someone who is disabled. What he is really asking is whether Munch or Van Gogh communicates the feelings of mental illness best. My experience with the Disabilities Awareness Newsletter has given me a good perspective on this question.

Getting to know kids with disabilities through my connection with this Newsletter has increased my respect for letting people with disabilities tell their own story. I have understood more about disabilities by



Vincent Van Gogh, *Corridor in the Asylum*

just listening than I could ever have imagined. It has been like looking at a piece of art work painted by a person with a disability. The artist's abilities are as clear as the disabilities. You see the whole picture.

When one of my peers with a disability writes an article or a poem or a piece of fiction I see how able she or he is to write and I also understand more about disability. There are opportunities to become more aware of disabilities where-ever we are and whatever we are doing. We should just look for chances to learn from one another.

SETTING MY HEART WITH THE STARS

by Jessica Terwilliger, Burnt Hills High School

This is the second time that I have written an article about depression for the disabilities awareness newsletter. Perhaps I feel compelled to write on the subject because it is a selfish disease. It seeps into every crevice of one's life; it refuses to be ignored, to be relegated to some obscure corner of the mind. Perhaps I'm writing about it because of what I have learned about my relationship with the disease. Perhaps the time has come when I'm ready to stop cursing the depression and start embracing it.



What I'm about to say is terribly unfashionable, and I hope that you will forgive any offense that it may cause. In all truthfulness, I'm glad that I have lived with depression as a companion. This statement does not imply that I have relished the grief and guilt the disease has borne. It does not mean that I have enjoyed the fits of despair, the self-imposed isolation, or the shared sorrow of my friends and family. I would not wish this illness upon anyone, yet I don't know if I could banish it from my own life, were I given the chance.

On a recent episode of ER, a physician who was deaf queried, "Did you ever think that being deaf might not be so bad?" She had accepted that her deafness was a part of her life, without allowing it to define who she was. For quite a while, I wasn't able to see my depression in that way. When it was first diagnosed, I didn't want to admit that this was something that would affect my existence. I wanted to rid myself of the illness immediately. As the years passed, however, I let myself become the incarnation of the disease. Lurking at the edge of my consciousness was the thought that I should resist the attempts to heal the depression. A part of me believed that if I let the medications and psychotherapy take the depression away from me, I would be lost. Rather than seeing myself as a person with depression, I saw myself as a depressed person. The distinction is subtle but significant.

I have finally reached the point where I can see both the horrors and the beauty of depression. It is something that should be neither glorified nor reviled. I am able to hate the illness for stealing away moments of my childhood while simultaneously appreciating the insight it has helped me to gain. Had I not known the absolute anguish it brought, I would not now recognize supreme happiness. Had I not experienced the heartache of personal defeat, I would not find such succor in emotional triumph. Had there not been times when I thought of killing myself, I would not now be in love with living. Reviewing various notable individuals who lived with a form of depression - F. Scott Fitzgerald, Henrik Ibsen, Mark Twain, George Frederic Handel, Robert Schumann, Robert Burns, Emily Dickinson, Victor Hugo, Dylan Thomas, Georgia O'Keeffe, Ray Charles, Francis Ford Coppola, John Kenneth Galbraith, Soren Kierkegaard - I can't help but wonder if their accomplishments were not just in spite of, but partially because of, their illness.

Oscar Wilde once wrote, "We are all in the gutter, but some of us are looking at the stars." I have reached a point in my life where I can concur with that sentiment. At last, I have realized that lying in the mud enhances the times when I've set my heart with the stars.

WE NEED YOUR HELP!!!

We are looking for creative dedicated students in grades 8-12 who are interested in writing articles, creating artwork, taking pictures, doing layout or designing websites. To find out more please contact us at:

Email: DAN@cqc.state.ny.us

Or

Attn: Disabilities Awareness Newsletter

NYS Commission on Quality of Care and Advocacy for Persons with Disabilities

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