

Awareness



of
Students with Diverse Learning Needs
What the Teacher Needs to Know

Volume 2



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This arrow indicates information that may be useful in an emergency situation.



This key indicates “key behaviour patterns” to watch for if you suspect one of your students may have a learning need as described in this document.



These hands indicate sources that will help you to find more information in your immediate community.

Acknowledgements

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About this document

The principle of inclusion adopted by British Columbia schools supports equitable access to learning for all students and the opportunity to pursue their goals in all aspects of their education.

Just as the companion first volume has done, this resource book contains information intended to assist classroom teachers in understanding the implications for classroom instruction and management of a number of diverse learning needs. Some students may have more than one of these needs in combination. Each section includes a definition, recognition signs, classroom strategies and contacts for more information. The three ring binder format has been used so that new or updated sections can be inserted as they become available and so that the reader can insert other information pertinent to an individual district, school or classroom.

The phrase diverse learning needs, used throughout this document, is meant to stand as a general term. It is not intended that this document be used as a resource for the reporting of students for supplemental special education funding purposes. Rather, this resource book is meant to be a practical support, building awareness of specific needs. It is not intended to be used as the final resource for teachers in this area, but rather as an introduction. It is important to emphasize that teachers are not responsible for diagnosis. They may, however, be the first to recognize symptoms and behaviours in the classroom. The focus is on ways that teachers can modify the learning environment to facilitate learning. Many of the suggestions are of a general nature.

The needs of a student with a diverse learning need such as has been described in this document will vary, depending on the type of learning need, the severity and, in some cases, the length of time that the student has had the learning need. Individual students have individual needs. It is important for teachers to be available to meet with a parent, and where appropriate, the student, to discuss any problems that may occur in the classroom, hopefully before they occur. The student may have already faced challenges in school and a solution may already have been found that works for him/her.

The strategies submitted are not, for the most part, suggestions of major changes to a teacher's style of teaching. However, it is hoped that the suggestions offered will help facilitate discussion and sharing of important information between the teacher and school-based team, teacher and parent and, as appropriate, teacher and student.



For More Information

From time to time a teacher may have a child with a rare disorder in the classroom. The following organization may be a resource for information:

The National
Organization for Rare
Disorders Inc. (NORD)
Box 8923
New Fairfield, CT.
06812-8923
USA

We want to know what you think!

Feedback on the usefulness of this resource book and suggestions for updates are invited. A feedback form is provided on the last page of this resource guide.

AIDS

AIDS (Acquired Immunodeficiency Syndrome) is a disease caused by the human immunodeficiency virus (HIV). The HIV virus attacks and gradually damages the body's immune system, its natural ability to fight illness, leaving it open to serious infections and cancer. AIDS represents the symptomatic phase seen in the later stages of HIV disease. No one has recovered from AIDS, although there have been some long-term survivors who have lived for long periods of time with HIV or AIDS. Research on treatment and the search for a cure for AIDS continues.

AIDS cannot be transmitted through casual contact. Transmission of the disease occurs in one of four ways: through unprotected sexual intercourse with an infected person; through contaminated blood or blood products or other body fluids; needle sharing for intravenous drug use; or congenitally through an infected mother to her baby. Therefore, according to The Oak Tree Clinic of B.C. Children's and Women's Health Centre, risk of transmission of HIV is extremely low in the school setting and in normal school interactions. Classroom teachers, other school personnel, and students should be familiar with universal precautions and should incorporate these precautions into everyday practice. Educating the community, students, and school personnel about HIV/AIDS remains the key component in effectively addressing HIV-related issues in the schools.

The number of adults, youth and infants both infected and affected by HIV continues to increase. The majority of children with HIV are being cared for and living at home. As well, the number of people surviving for longer periods of time is increasing due to treatment advances such as better medication and improved efforts in nutritious and supportive care of the person with HIV. For schools, this means there will be increased numbers of students who are either infected with HIV and/or have a family member infected with HIV.

Some medical treatment used with children and adolescents with HIV/AIDS may have considerable impact upon the classroom participation of the student. For many, there are frequent trips to a hospital clinic, blood tests, daily medications, and periods of feeling ill.

Several medications are used to treat individuals who are HIV positive or have AIDS. AZT (zidovudine) and DDI (didanosine) are commonly used medications that slow the replication of the HIV virus.

Educating the community, students and school personnel about HIV/AIDS remains the key component in effectively addressing HIV-related issues in the schools.

Recognizing the Needs of a Child with HIV/AIDS

Most children with HIV at school will be asymptomatic with no signs or symptoms. Children with HIV disease will experience a wide range of symptoms as a result of the damaged immune system, including: recurrent ear infections, sinusitis, non-infectious skin rashes, intermittent diarrhea, poor appetite and poor weight gain.

In addition to its effects upon the immune system, HIV has been found to affect the nervous system directly. Between 50 and 90 percent of children with AIDS develop such complications, including: cognitive deficits; motor problems with gait or balance; expressive language deficits; impaired attention; and increased distractibility, excitability and impulsiveness. Every system can be affected by the HIV infection, including the respiratory, cardiovascular, gastrointestinal, renal, endocrine, locomotor systems, as well as the skin and the central nervous system.

Children with congenital HIV/AIDS are at risk because they are unable to mount a proper antibody response. Certain minor illnesses easily acquired by others, such as measles, can be fatal to a child with AIDS. Students who have AIDS are at far greater risk of acquiring these infections. For this reason, it is important that school personnel take every precaution to avoid exposure of a child with AIDS to other children who are ill.

The psychosocial effects shown by students and families affected by AIDS are also many and varied, including swings in mood and behaviour, feelings of isolation, fear, depression, grief, anger, and guilt. These emotional reactions can arise not only from within the student, but can also be increased or lessened by the reactions of family members, teachers, peers, and other people in the community. Many children and adolescents with HIV/AIDS attain a sense of courage and clarity through facing their fears about loss, death and separation.

An important consideration in the design of educational programs may be improvement of quality of life. Through understanding and support, teachers can help children to cope with their unique stresses induced by HIV, to develop relationships and make choices, and to gain a sense of independence and control over their environment.

Classroom Strategies

- Meet with parents, the student and professional treatment staff to help determine how best to meet the individual needs of the student. These may include physical, communication, learning, daily living, behavioural and social needs. Maintaining clear, unambiguous communication will be an essential part of this process.
- Identify someone at the school to liaise with the student's treatment team. This will help in determining the student's ongoing needs and the ability to support them on a continuing basis.
- Develop an Individual Education Plan (IEP) specific to the student's needs. Regular monitoring of this plan will be essential.
- Become familiar with the school's policy and guidelines regarding the presence of HIV-infected students and staff in the school.
- Examine and reflect on your own attitudes about persons with HIV/AIDS. The classroom climate enhances the student's participation.
- Consider inviting a guest speaker from an organization which supports persons with HIV/AIDS to talk about the disease, to provide information (including brochures and other media) and to facilitate understanding.
- Be familiar with universal precautions for blood and body fluids, which should be incorporated into everyday practices.
- Instruct all students on proper infection control procedures and self-help skills, such as hand washing and covering the mouth when sneezing or coughing.
- Work around treatment schedules so that the student may feel a part of the constant flow of the classroom.
- Be flexible with tests and classwork. Absences because of illness, hospitalization and clinic visits may be necessary.
- Provide flexibility in academic subjects as necessary in order to reduce workload and hence the student's anxiety and stress.
- Allow more rest breaks or shorter assignments for students who are feeling ill or who tire easily.
- Provide assignments with deadlines and constant progression through a lesson to help students develop a sense of order and future.
- Establish expectations, with respect to assignments and study routines, through discussions with the student and her/his parents.
- Recognize that these students may be insecure with concepts or materials previously understood.



Universal Precautions for Blood and Body Fluids

The British Columbia Ministry of Health and Ministry Responsible for Seniors recommends that the universal precautions for infectious blood and body fluids be taken and incorporated into everyday practice to prevent any chance of transmission. These precautions are described as universal because they should be applied to all persons, situations, or conditions.

1. Wear latex, vinyl or rubber disposable gloves when handling blood or blood-stained materials, especially if you have open cuts or chapped hands.
2. Use disposable absorbent material to stop bleeding, or to remove most of the spill.
3. Wash hands thoroughly with soap and water immediately after removing gloves and dispose of the gloves and blood-stained materials in a clearly identified, impervious, plastic bag and discard in a lined, covered garbage container.
4. Handle contaminated clothing cautiously and machine wash separately in hot soapy water.
5. Keep all cuts and open wound covered with clean bandages.
6. Avoid smoking, eating, drinking, nail-biting, and all hand-to-mouth, hand-to-nose, and hand-to-eye contact when working in areas contaminated with blood.



Universal Precautions Continued

7. Clean up any spills of blood thoroughly and promptly, and clean all possible contaminated surfaces and areas with a 1:10 household bleach dilution or an approved disinfectant. For carpets or upholstery that may be damaged by bleach other germicides or disinfectant agents can be used. Soak mops or brushes that have been used for cleaning in a disinfectant for 20 minutes.
8. Never share toothbrushes, razors, or other items that might transmit blood.
9. Avoid needle sticks and other sharp instrument injuries. Never re-cap, bend or break off used needles. Discard syringes or needles in a safe, puncture-proof container.

Not all body fluids are infectious. Urine, feces, nasal secretions, tears, saliva or vomit, are not infectious unless visibly blood-stained. However, in some situations you may prefer to wear gloves. Remember, it is always important to wash your hands carefully after touching body fluids, even if you have worn gloves.

- If the student develops physical or sensory disabilities as a result of an infection, incorporate appropriate adaptations to enhance the student's success in the school.
- For children who are ill, work with the hospital/homebound teacher to help the absent student to stay organized and informed as to assignments and activities. Consider the use of audio homebound or audio-visual hook-up as a method of instruction.
- Expect appropriate behaviour: all students are accountable for their behaviour.
- Supportive counselling is considered a critical component in a comprehensive approach to the AIDS challenge. Children may have to deal with parental or sibling illness and death, stigma induced isolation from peers/adults, the prospect of facing their own disability and death.
- Reduce stress overall for the student. Be alert to physical symptoms such as irritability, agitation, and overreaction to minor occurrences.
- An increase in unusual or difficult behaviours may reflect an increase in stress, or a feeling of loss of control. The individual may need to go to a quiet, less stimulating environment and/or "safe person".
- Be sensitive to the emotional needs of the student who is adjusting to a change of lifestyle (e.g., shock and denial, fear, anger, guilt, depression, acceptance).
- Allow the child to leave the classroom as needed in an independent manner without drawing attention to themselves.
- Maintain contact with the student if s/he is hospitalized, particularly if the student is away for several months. Letter writing may help classmates to keep social contact and remain comfortable with students when s/he returns to the school setting.
- Help the student with his or her transition back into the classroom, especially after a long absence, by maintaining open lines of communication. Let them know you are thinking of them and making preparations for their return.
- Consider the need for assistance with your own emotional reactions in the event of a child's death.
- If the child's condition worsens, and survival is no longer certain, it is important to remember that continued school participation is vital to the child's self-worth and overall sense of well-being.
- Develop a plan for dealing with the possibility of a child's death that takes into consideration the needs of the child's classmates, teachers and other school staff, siblings or relatives of the deceased child who may attend the school, and the child's family.

- Siblings of children with HIV/AIDS are impacted profoundly by the illness of their brother or sister. If you are the teacher of a sibling of a child with HIV/AIDS, it is important to be aware of the situation at home and to make the parents aware of changes of behaviour (e.g., acting out) or changes in performance (e.g., falling grades) at school.
- Confidentiality is very important. In most cases the family and/or the student may wish to keep the fact that they are living with HIV/AIDS confidential. It is very important that the student's confidentiality be respected and that his/her situation is not discussed with other teachers, students or parents of other students.



For More Information

Contact health care professionals through your local Child Development Centre and/or public health unit.

Contacts

Persons with AIDS Society of BC/Positive Womens Network/AIDS

Vancouver

c/o Pacific AIDS Resource Centre
1107 Seymour Street
Vancouver, B.C. V6B 5S8
Tel: (604) 681-2122
Fax: (604) 893-2251

The Oak Tree Clinic: The Women and Family HIV Centre Children's and Women's Health Centre British Columbia

4480 Oak Street
Vancouver, B.C. V6H 3V4
Tel: (604) 875-2345

YouthCO AIDS Society

203-319 West Pender Street
Vancouver, B.C. V6B 1T4
Tel: (604) 688-1441
Fax: (604) 688-4932

Cancer

The term cancer refers to a collection of diseases that have in common uncontrolled cell growth and the ability to invade the body. This ability to invade and destroy the normal tissue or body organ means that cancer is fatal if left unchecked. Children with cancer find their bodies are affected in various ways and in various locations depending on the type of cancer. Each year in Canada, an estimated 1,330 children and teens are diagnosed with some form of childhood cancer. Current estimates suggest that ten thousand children and teens are living with some form of cancer.

The type of cancer and its severity will determine the treatment provided. Primary treatment options usually consist of a combination of medication, radiation therapy, and surgery. Because of the treatment, side effects, or complications of the cancer, the child with cancer may have frequent absences from school and periodic hospitalizations. Changes in the course of the illness and its treatment bring about problems common to other chronically ill students and their families, but with cancer there may be an increased emotional strain because of the stigma and the fear evoked by the disease.

Over the last three decades, advances in treatment have been significant. Today, more than 71% of children with cancer will survive five years or longer and most will be cured. Even when the student may not survive, maintaining a supportive educational environment is paramount. For some students with cancer, going to school is vital because of the importance school has in his or her life as a positive environment. Returning to school can be an activity that signals to everyone that the child's life is moving forward.

Many children and adolescents with cancer attain a sense of maturity and sensitivity far beyond their years. The fact that they have been forced to handle both the normal challenges of growing up as well as their physical care may give them extra doses of self-discipline. Through understanding and support, a teacher can help the child to cope with their unique stresses induced by cancer and to develop emotionally, socially and academically to their full potential.

Over the last three decades, advances in treatment have been significant. Today, more than 71 percent of children with cancer will survive five years or longer and most will be cured.

Types of Cancer Found in Children

Knowing some of the more common types of cancer, their treatment and prognoses, may allow the teacher to address the needs of the student with cancer more effectively.

| Type | Definition | Treatment | Chance for Cure |
|---|--|---|--|
| Acute Lymphoblastic Leukemia (ALL) | <ul style="list-style-type: none"> Cancer of the blood cells (lymphocytes) arising in bone marrow. | <ul style="list-style-type: none"> Combination of chemotherapy drugs. Radiation for some at high risk. | <ul style="list-style-type: none"> 95% will obtain complete remission. 70-90% of children will obtain a long-term remission and be cured. |
| Acute Nonlymphoblastic Leukemia (ANLL) | <ul style="list-style-type: none"> Cancer of the blood cells arising from any blood cells other than lymphocytes. | <ul style="list-style-type: none"> Combination of chemotherapy drugs. If a healthy sibling has the same genetic makeup, the child may be a candidate for a bone marrow transplant. | <ul style="list-style-type: none"> 80-85% will obtain a complete remission. 30-40% will obtain long term remission with chemotherapy alone. 60-70% will obtain a long-term remission with a bone marrow transplant. |
| Central Nervous System Tumours | <ul style="list-style-type: none"> Tumours arising in the central nervous system, i.e., brain tumours and tumours of the spinal cord. | <ul style="list-style-type: none"> Surgical removal if possible, radiation therapy and/or chemotherapy in some cases. | <ul style="list-style-type: none"> Overall long-term survival is variable and dependent on tumour size, location, and type as well as disease spread, amount of tumour removed and response to treatment. |
| Hodgkin's Lymphoma | <ul style="list-style-type: none"> Cancer involving the lymphatic tissue. Originates in the lymph nodes. | <ul style="list-style-type: none"> Chemotherapy with or without radiation depending on the stage of the disease. | <ul style="list-style-type: none"> Cure rates range upwards from 80% depending on the progression of disease at diagnosis. |
| Non-Hodgkin's Lymphoma | <ul style="list-style-type: none"> Cancer involving the lymphatic tissue. Originates in lymphocyte cells in the lymph nodes. | <ul style="list-style-type: none"> As with Hodgkin's above. | <ul style="list-style-type: none"> 50-90% depending on disease progression at diagnosis. |
| Soft Tissue Sarcoma | <ul style="list-style-type: none"> Cancer of connective tissue which can arise almost anywhere in the soft tissues of the body. | <ul style="list-style-type: none"> Surgery if possible, chemotherapy, radiation may be used in some cases. | <ul style="list-style-type: none"> Overall rate of cure is 70% with rates varying depending on stage and location. |
| Bone Sarcoma | <ul style="list-style-type: none"> Tumours arising in cells that eventually mature into bones. Tumours can involve surrounding tissue. | <ul style="list-style-type: none"> Treatment involves chemotherapy and surgery. Radiation may be used if surgery is not possible. Surgery may involve limb saving or amputation. | <ul style="list-style-type: none"> Dependent on location and disease progression. Overall long-term survival rate is 60-70% |
| Neuroblastoma | <ul style="list-style-type: none"> Tumours of the sympathetic nervous system. Arises in embryonic neuronal cells in the neck, chest, abdomen or pelvis. | <ul style="list-style-type: none"> Surgery. Chemotherapy and sometimes radiation if the disease has spread. The role of bone marrow transplantation is being explored. | <ul style="list-style-type: none"> Long-term disease-free survival rates of more than 90% in children with localized neuroblastoma. Overall long-term survival rate is 60% |
| Wilms Tumour | <ul style="list-style-type: none"> Cancer of the kidney. | <ul style="list-style-type: none"> Surgery and chemotherapy, with or without radiation. | <ul style="list-style-type: none"> Overall cure rates over 85% Survival rates of 60-70% even when spread at presentation. |

Adapted from *Helping Schools Cope with Childhood Cancer: Current Facts and Creative Solutions*, produced by Paediatric Division of Victoria Hospital, London, Ontario, Canada, 1996.

Treatment of Children with Cancer

The treatment of children and adolescents with cancer takes three basic forms: surgery, medication (chemotherapy and steroids), and radiation therapy. In specific circumstances, a bone marrow transplant may be part of the treatment. Without treatment, cancer will kill the individual because it is invasive and disrupts normal body functions. With treatment, especially after early detection, many cancers are curable. These treatments need to be considered for their impact upon the classroom participation of the student.

Surgery

Historically, surgery has been the primary treatment for cancer. Surgery is performed to determine if a tumor is malignant or benign, to remove the tumour if cancer cells are found, and to assure that the cancer has not spread to surrounding organs. Surgery is often combined with radiation and chemotherapy. Some surgical procedures, such as limb amputation, can cause significant physical and psychological trauma in children. Teachers will need to be extremely mindful of the psychological needs of the student who is returning to school and who may have experienced such a loss.

Chemotherapy

This treatment for cancer, which uses chemicals toxic to cells, can cause unpleasant side effects, including nausea, vomiting and hair loss. The recent development of new medications to treat these complications has greatly improved the quality of life of individuals going through chemotherapy. Where hair loss does occur, it can be traumatic and can negatively affect body image. Usually, peer education is needed to provide information and sensitization to support the student.

Radiation therapy

This treatment for cancer uses X-rays to cause cell destruction. Radiation may be delivered by an external beam concentrated on the area where the cancer is located, through the use of implants or, in some cases, in the form of radioactive solutions taken orally or injected. Side effects may include fatigue, achy feelings, nausea, vomiting, dry mouth, and several longer term side effects, including possible learning difficulties.

Bone marrow transplantation

Bone marrow transplantation is used to rescue the individual after high dose chemotherapy and radiation therapy have been administered. A bone marrow transplant restores the bone marrow. Side effects can include infection, organ distress, and graft-versus-host disease.

Classroom Strategies:

- Meet with parents, the student and professionals in the community to help determine how best to meet the individual (emotional, physical, communication, learning, daily living, behavioural and social) needs of the student.
- Obtain the following information:
 - the type of cancer, including its prognosis;
 - the type of treatment, including the side effects;
 - the schedule of treatments and tests that require absences;
 - any special medical precautions;
 - a list of any physical limitations on the student's activities; and
 - an understanding of what the child has been told about the disease.
- Develop an Individual Education Plan (IEP) specific to the student's needs.
- Be aware that some chemotherapy and/or radiation therapy treatments can cause cognitive 'late effects' on children with cancer. Ongoing formal psychoeducational evaluations will be important to help assess the student's educational needs.
- Be sensitive to the emotional needs of the student who is adjusting to a change of lifestyle (e.g., anger, depression, disappointment).
- Try to develop and project a positive attitude of hope. Your optimism will be relayed to the child with cancer, classmates and others in the school community.
- Talk with the student about whether s/he wishes to discuss his/her illness in the classroom. The student may be fearful about being seen as "different" by either peers or teachers.
- Consider inviting a guest speaker, a local health nurse or representative from the Canadian Cancer Society, to talk about and facilitate an understanding of cancer, and to provide the school with informational brochures and other media.
- Where appropriate, provide the student's peers with information and sensitization to engender support for the student and to promote peer interaction.
- Siblings of children with cancer are impacted profoundly by the illness of their brother or sister. If you are the teacher of a sibling of a child with cancer, it is important to be aware of the situation at home and to make the parents aware of changes of behaviour (e.g., acting out) or changes in performance (e.g., falling grades) at school.
- Allow the child with cancer to leave the classroom as needed in an independent manner without drawing attention to themselves.

- Designate a staff person, a counsellor, school nurse, or someone in the office, that the student can go to if they are feeling physically or emotionally uncomfortable.
- Work around treatment schedules so that the student may feel a part of the constant flow of the classroom.
- Recognize that the student may have gaps in their knowledge of certain subjects as a result of absences due to illness, appointments and treatment. Be aware of material missed, so that the student may remain current with his or her peers.
- Be flexible with tests and classwork. Absences because of illness, hospitalization and clinic visits may be necessary.
- Allow more rest breaks or shorter assignments for students who are feeling ill or who tire easily.
- For children who are ill, consider the use of audio homebound or audio-visual hook-up as a method of instruction.
- Maintain contact with the student when s/he is at home or in the hospital. Letter writing may help classmates to keep social contact and remain comfortable with students when s/he return to the school setting.
- Work with the hospital/homebound teacher to help the student to stay organized and informed as to assignments and activities.
- Help the student with his or her transition back into the classroom, especially after a long absence, by maintaining open lines of communication. Let them know you are thinking of them and making preparations for their return.
- Consider the range of different emotional reactions that children and adults may display, so that when the student does return to school s/he feels as though they are part of the "normal" routine.
- Assign "peer helpers" to aid in mobility needs, or to work together with the homebound or hospitalized student on missed assignments.
- Provide assignments with deadlines and constant progression through a lesson to help students develop a sense of order and future.
- School trips, outings and long bus rides can present problems with washroom facilities. The student may have to miss these occasions, especially during times of "flare-up".
- Limit or skip strenuous physical education programs. Suitable activities can be determined in consultation with the student's parents and the student.

- If the child's condition worsens, and survival is no longer certain, it is important to remember that continued school participation is vital to the child's self-worth and overall sense of well-being.
- Consider the need for assistance with your own emotional reactions in the event of the painful possibility of a child's death.
- Develop a plan for dealing with the possibility of a child's death that takes into consideration the needs of the child's classmates, teachers and other school staff, siblings or relatives of the deceased child who may attend the school, and the child's family.

Contacts

Further information can be obtained from an appropriate health care professional or a representative from the following agencies:

**Department of Paediatric Oncology
Children's and Women's Health Centre British Columbia**

4480 Oak Street
Vancouver, B.C. V6H 3V4
Tel: (604) 875-3575

Canadian Cancer Society B.C. & Yukon Division

Education Department
565 - West 10th Ave.
Vancouver, B.C. V5Z 4J4
Tel: (604) 872-4400
Fax: (604) 879-4533

The Candlelighters Childhood Cancer Foundation of Canada

Suite 401, 55 Eglinton Avenue East
Toronto, Ontario M4P 1G8
Tel: (416) 489-6440
1-800-363-1062
Fax: (416) 489-9812



**For More
Information**

Contact health care professionals through your local Child Development Centre and/or public health unit.

Chronic Fatigue Syndrome

Children with chronic fatigue syndrome (CFS), as the name suggests, experience profound exhaustion and poor stamina. As a result, they have a substantial reduction in their ability to address personal, social, educational, and occupational expectations. Other common characteristics seen in children with this syndrome include pain, cognitive deficits, environmental sensitivities and increased susceptibility to infections.

Symptoms of this syndrome may occur at a young age, but are often not readily observed because young children do not have the language to explain or describe their symptoms. Additionally, parents and teachers often lack a reliable reference point to compare current levels of activity or function with previous ones because children are continually changing as they grow. For the majority of children, and particularly adolescents, CFS begins with a sudden onset of symptoms, usually a flu- or mononucleosis-like illness in a child who had previously been well. In younger children, CFS may appear gradually over several months starting with mild symptoms such as sore throats, headaches, joint pain and/or increasing fatigue.

Because the symptoms of CFS often occur during a period of rapid intellectual development, children may experience long term difficulties with their cognitive functioning. Their ability to concentrate for long periods of time is severely compromised. The students may experience difficulty with headaches, bright lights, noise, temperature, odours, a worsening of pre-existing allergies, visual/spatial distortions, word recall difficulties, word transposition, geographic disorientation, or difficulty with calculations. Students may also be easily distracted and unable to maintain attention and may have significant difficulty processing information. As a result, they may have problems with conversations or reading. They may only be able to concentrate for short periods of time. Walking from one classroom to the next, sitting upright in class, participating in class activities, and socializing with classmates can be draining, leaving little or no energy for learning.

Recognizing CFS in children requires the skills of appropriately qualified medical personnel experienced with this condition. Without such experience, the symptoms can be confused with those of other disorders, resulting in a possible misdiagnosis, such as mononucleosis, attention deficit disorder, Crohn's disease, lupus, atypical depression or childhood migraine syndrome. Changes in symptoms and their intensity, and the relapsing and remitting pattern of this chronic health problem, also sometimes lead to an inaccurate impression of behavioural or emotional problems, and an interpretation by medical and school personnel of laziness, school phobia, emotional disturbance and/or lack of motivation.

An early medical diagnosis is important to make the invisible symptoms of chronic fatigue syndrome more visible. Early collaboration among

Symptoms of this syndrome may occur at a young age, but are often not readily observed because young children do not have the language to explain or describe their symptoms.

professionals, including the classroom teacher, occupational/physical therapist, counselor, learning assistance room teacher, and family physician, will help in developing appropriate learning strategies for the student. The teacher, the parent and the child need to understand the child's physical and neurological status, and the strategies developed. A combination of medication, lifestyle changes, dietary restrictions, nutritional supplementation, supportive therapy, and a school/home focused educational program is often recommended.

Recognizing the Child with Chronic Fatigue Syndrome

Symptoms may vary from person to person and fluctuate in severity. A diagnosis by appropriately qualified medical personnel is needed to verify the condition.

According to the case definition for CFS published in the December 15, 1994 issue of the *Annals of Internal Medicine*, unexplained chronic fatigue can be classified as CFS if, after a thorough medical evaluation, the individual meets the following criteria:

- Clinically evaluated, unexplained persistent or relapsing chronic fatigue that:
 - is of new or definite onset (i.e., not lifelong);
 - is not the result of ongoing exertion;
 - is not substantially alleviated by rest; and
 - results in substantial reduction in previous levels of occupational, educational, social or personal activities.
- The concurrent occurrence of four or more of the following symptoms:
 - substantial impairment in short-term memory or concentration;
 - sore throat;
 - tender lymph nodes;
 - muscle pain;
 - stomach aches;
 - multi-joint pain without joint swelling or redness;
 - headaches of a new type, pattern or severity; unrefreshing sleep; and
 - post-exertional malaise lasting more than 24 hours.

These symptoms must have persisted or recurred during six or more consecutive months or illness and must not have predated the fatigue.



Key Behaviour Patterns

- Unexplained persistent or relapsing fatigue.
- Word transposition.
- Geographic disorientation.
- Easily distracted and unable to maintain attention.
- Only be able to concentrate for short periods of time.
- Difficulty with headaches, bright lights, noise, temperature, odours and/or worsening of pre-existing allergies.

Classroom Strategies

- Meet with the parents and the student as early in the school year as possible to determine how best to meet the individual (emotional, physical, learning, daily living, behavioural and social) needs of the student.
- Develop an Individual Education Plan (IEP) specific to the student's needs.
- Ask the school nurse, or a doctor for information and assistance.
- Maintain ongoing communication with other members of a multi-disciplinary special education evaluation team: these may include para-professionals and health care professionals (school nurse, homebound program teacher, occupational therapist, physical therapist, school counsellor, physician, and psychologist).
- Explain to the class what CFS is and how it is treated. Support and understanding from peers will help overcome feelings of isolation, rejection or embarrassment.
- Recognize that these students may be insecure with concepts or materials previously understood.
- For the secondary student in particular, consider planning a reduced course load and shortened day or well-placed rest periods to decrease fatigue and stress related to academic demands.
- Have more difficult subjects scheduled earlier in the day when students are more alert.
- Allow extra time to get from room to room, and to complete tests.
- Have two sets of books: one at home and one at school so students don't have to carry them home.
- Encourage the use of assistive devices, including computers, calculators, tape recorders, and other assistive learning devices. The computer, in particular, can serve as a compensatory tool in the classroom.
- Allow the student to videotape presentations to the class in advance.
- Limit or skip strenuous physical education programs. Suitable activities can be determined in consultation with the student's parents and the student.
- Allow the child to leave the classroom as needed in an independent manner without drawing attention to themselves.
- Modify homework assignments to accommodate reduced energy levels and impaired concentration. For example, shorten math homework from 30 problems to 10.

- Plan for success: break tasks into manageable sequential steps the student can handle, with frequent breaks which can be seen as rewards for appropriate behaviour. Provide a sequential checklist for longer assignments and projects.
- Frequent breaks can be created by allowing the student with CFS to compare responses with a strong student on assignments that require drill and practice such as math questions.
- Help the student to stay organized and informed as to assignments and activities. Provide copies of instructions and expectations for assignments and provide extra help where necessary.
- Be flexible with tests and classwork: provide extra time for tests and assignments, permit make-up work
- Provide the student with a syllabus or schedule of upcoming assignments so s/he can keep up with the class when unable to attend school.
- Involve the student in scheduling, and set flexible class schedules and assignment deadlines.
- Give as much warning as possible to the student about up-coming projects and/or large assignments.
- Eliminate as much as possible competing stimuli — keep desks clear, set up a study carrel, reduce noise as much as possible, maintain a comfortable temperature, good quality lighting which doesn't cause glare. A quiet seat in close proximity to the teacher could assist the student in staying on task.
- Offer a screened corner to your class as an earned privilege during scheduled times rather than a punishment. This avoids segregating the child who may need the screened corner to reduce distractions.
- Allow the student more time to move between classes, when changing classrooms is required.
- Provide an extra set of textbooks for the student to use at home.
- Encourage the use of a multi-modal approach to learning, i.e., using finger to follow the sentences, and saying them out loud as the student reads.
- Create opportunities for the student to participate in normal childhood experiences, such as attending school dances, participating in field trips, and socializing with friends.
- Be sensitive to the emotional needs of the student who is adjusting to a change of lifestyle (e.g., anger, loss, depression, acceptance).

- Work with the school counsellor to identify and develop effective coping strategies for stress management.
- Encourage the student to employ stress management practices to alleviate stress, test anxiety, performance anxiety, etc., i.e., use of imagery and deep breathing periodically during the day and before examinations.
- For children who are ill, work with the hospital/homebound teacher to help the absent student to stay organized and informed as to assignments and activities. Consider the use of audio homebound or audio-visual hook-up as a method of instruction.
- Consider videotaping early morning classes or other required classes that the student is not able to attend so that the student can “attend” them at home.

Contacts

Myalgic Encephalomyelitis Society of BC

327A Evergreen Drive
Port Moody, B.C. V3H 1S1
Tel: (604) 937-7017
Fax: (604) 937-7015

The CFIDS Association of America

P.O. Box 220398
Charlotte, NC 28222-0398
Tel: (704) 365-2343
Fax: (704) 365-9755
<http://www.cfids.org>



For More Information

Contact health care professionals through your local Child Development Centre and/or public health unit.

Eating Disorders

Anorexia nervosa and bulimia nervosa are serious eating disorders that typically arise during the adolescent years. A central feature of both disorders is the extreme preoccupation these individuals exhibit towards their weight and shape. This includes a drive for thinness and an excessive fear of becoming fat. In addition to low self-esteem, distorted attitudes toward the body and self, and feelings of ineffectiveness may be present.

Eating disorders may be viewed in part as extreme expressions of a range of weight and food issues that many individuals experience. They are complex illnesses determined by a variety of risk factors which are not well understood. These include:

- the continuing media promotion of thinness as healthy and a sign of success;
- perfectionism;
- highly competitive environments which stress body thinness and high performance; experiences of loss in personal relationships, such as family break-ups or losses of family members;
- a low sense of self-esteem; and
- heightened concern for appearance and body shape when adjusting to the physical changes of puberty.

A child or adolescent with anorexia nervosa has a marked fear of weight gain, becoming fat, or even of achieving a normal body weight, even though they are below their expected weight. The person's self-esteem is closely tied to their weight and shape. They experience their weight or shape as larger than it actually is (often describing themselves as "fat"), or they are unable to appreciate the serious nature of their degree of malnutrition. Children and adolescents with anorexia nervosa may solely restrict their caloric intake, or may in addition experience episodes of binge-eating and purging, the latter most commonly through self-induced vomiting.

An adolescent with bulimia nervosa will engage in episodes of binge-eating, these involving a sense of loss of control over eating. Binge-eating almost always occurs in secret, because the individual knows that the behaviour is not "normal" and feels guilty. The episodes of binge eating are followed by episodes of compensatory purging. This may be through self-induced vomiting, rigid dieting, fasting, use of laxatives, or excessive exercise all of which are counterproductive and harmful. As with anorexia nervosa, the individual's self-esteem is closely tied to issues of their body weight and shape.

It is important to recognize that these behaviours signal the distress the individual is experiencing and function as coping mechanisms for them. Treatment of eating disorders should involve early collaboration by the student and family, and an interdisciplinary team of professionals (e.g., family physician, psychologist, nurse, pediatrician, social worker, dietitian,

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psychiatrist, youth care worker, occupational therapist, teacher and support staff). Educational programming that is integrated, interdisciplinary and individualized will ensure that the opportunity for successful recovery is enhanced for students with eating disorders.

Although the most common age of onset of bulimia nervosa is between 14 and 25, there have been reports of early-onset bulimia nervosa (10 to 15 years) and anorexia nervosa occurring in young children prior to puberty. The prevalence of anorexia nervosa is reported to be .48 per cent or about 1 in 200 girls (ages 15-19 years), making this illness the third most common chronic condition in this age group. The prevalence of bulimia nervosa in young women is around one to three per cent. The majority of sufferers of eating disorders are females.

Eating disorders are best viewed as complex illnesses which reflect the interplay between biological, psychological, and social factors. Their severity needs particular emphasis. Data from adult samples indicates that anorexia nervosa has the highest mortality rate (exceeding 10 per cent) of any psychiatric condition. Death may occur through the longer-term effects of chronic malnutrition or through suicide. Individuals who purge may develop problems with electrolytes, such as low levels of potassium, which may have fatal consequences. An eating disorder may interfere markedly with the achievement of the normal developmental milestones of adolescence.

Children and adolescents with eating disorders, while often highly achievement oriented and perfectionistic in school, may exhibit the usual range of cognitive strengths and weaknesses and may have learning disabilities. The effects of starvation may be severe and accentuate the stresses these students experience in the school setting. Many of the cognitive and affective (mood) characteristics listed below are due to the effects of malnutrition.

This material was prepared by Ronald S. Manley, Ph.D., R. Psych., Heidi Rickson, B.Sc., B.Ed., and Bill Standeven, M.A.

Ronald S. Manley is the Clinical Director of the B.C. Children's Hospital Eating Disorders Program, and Heidi Rickson is the teacher in the Day Treatment Program at the B.C. Children's Hospital Eating Disorders Program. Bill Standeven is a Coordinator with Special Programs Branch, Ministry of Education. We would like to thank Dr. Jorge Pinzon, Marigrace Rennie, B.A., and Denzil Jones, B.A., B.Ed., for their helpful comments on an earlier draft of this paper.

Understanding the Child or Adolescent with an Eating Disorder

The diagnosis of anorexia nervosa or bulimia nervosa requires an assessment by skilled and experienced health professionals. There are several medical and psychiatric conditions that may appear to be anorexia nervosa. For example, a child may experience appetite loss as a result of depression or be unable to eat due to severe anxiety unrelated to weight or shape concerns.

The following typical characteristics, although not an exhaustive listing, may be helpful in recognizing and better understanding the symptoms an individual may experience. Caution with respect to their use is essential. Not all symptoms will be evident with all individuals.



| | | |
|--------------------|---|---|
| Behavioural | <ul style="list-style-type: none"> • May set very high goals for themselves • Significant weight loss • Restrictive eating pattern (dieting) • May be binge eating/purging • Excessive exercise • Increased social isolation • Avoidance of eating situations • Easily fatigued | <ul style="list-style-type: none"> • May set very high goals for themselves • May be weight fluctuations • Restrictive eating pattern (dieting) • Binge eating/purging • May be excessive exercise • Often more socially outgoing |
| Cognitive | <ul style="list-style-type: none"> • Difficulty concentrating due to preoccupation with food, calories, weight or shape. • Seeing things in an all-or-none, black and white fashion. • Difficulty retaining information • Indecisive | <ul style="list-style-type: none"> • Difficulty concentrating due to preoccupation with food, calories, weight or shape • Seeing things in an all-or-none, black or white fashion |
| Affective | <ul style="list-style-type: none"> • May feel like a failure if anything is less than "perfect" • Depression • Anxiety • Mood swings • Irritability • Poor self-esteem • Sense of shame or guilt about the eating disorder | <ul style="list-style-type: none"> • May feel like a failure if anything is less than "perfect" • Depression • Anxiety • Mood swings • Irritability • Poor self-esteem • Sense of shame or guilt about the eating disorder |

If you are concerned about a student, consult with a member of the school based team regarding their referral process. The student and family may then be referred for more specialized assessment. Treatment may be lengthy and difficult for both the student and her/his family, and they will benefit from continued support. On-going medical and nutritional monitoring will be important, and the mainstay of treatment and the prevention of relapse will be continued psychotherapy, likely a combination of individual and family therapy.

Classroom Strategies

- If a student in your class has been diagnosed as having an eating disorder, consider the following strategies:
- Identify someone at the school to liaise with the child or adolescent's treatment team. This will facilitate determining the student's ongoing needs and the ability to support them on a continued basis.
- Meet with parents, the student and professional treatment staff to help determine how best to meet the individual (emotional, physical, learning, daily living, behavioural and social) needs of the student. Maintaining clear, unambiguous communication will be an essential part of this process.
- School personnel may need to liaise with the treatment team around the student's activity level. For example, the student's level of participation in physical education classes may need to be adjusted depending on the severity of their illness.
- Develop an Individual Education Plan (IEP) specific to the student's needs.
- Examine and reflect on your own attitudes about body image, weight and shape. Model healthy attitudes toward bodies and food. Maintain zero tolerance of appearance-based jokes, taunts and harassment.
- Do not expose students to situations that may produce considerable turmoil for them, such as weighings, doing skinfolds, etc. Avoid dwelling on food related discussions and avoid commenting on weight or appearance as it may not be taken in the intended context.
- Be alert to the sense of shame and guilt that these students may experience in relation to having an eating disorder.
- Maintain contact with the student if s/he is hospitalized during the course of their eating disorder, and if the student is away for several months to attend more intensive treatment, such as a day treatment program. Letter writing may help classmates to keep social contact and remain comfortable with students when they return to the school setting.
- Help the student with his or her transition back into the classroom, especially after a long absence, by maintaining open lines of communication. Let the student know you are thinking about him or her and making preparations for his or her return.
- Work with the hospital-homebound teacher or day treatment program teacher to help the student to stay organized and informed as to assignments and activities.
- Be flexible with tests and class work. Absences to attend medical/therapy appointments may be necessary.

- Recognize that students with eating disorders may be rigid in their thinking and tend to set unrealistically high standards for their academic work. They may, as a result, experience marked distress with respect to their schoolwork. It is helpful to support such a student in adopting a more moderate approach to their schoolwork. Recognize that their need to do exceptionally well may arise from a poor sense of self-esteem.
- In some cases it will be helpful to discourage obsessive study habits, and encourage a healthy balance between peer relationships, school, and extramural activities.
- Establish expectations with respect to assignments and study routines via discussions with the student and her/his parents.
- Use visual timelines to help students develop time management skills and appropriate study routines.
- Recognize and understand that they may be experiencing the effects of starvation, making concentration on schoolwork particularly difficult.
- Recognize that these students may be insecure with concepts or materials previously understood.
- Work with and support the student with respect to peer relationships and social activities. Students with eating disorders may feel that they do not fit in at school and be relatively socially isolated.
- Anticipate problems before behaviour can escalate out of control. There may be times when these students are moody or depressed. Some students with eating disorders may experience anxiety attacks.
- Provide flexibility with respect to academics in order to reduce workload and hence the student's anxiety and stress.
- Reduce stress overall for the student. Be alert to physical symptoms such as irritability, agitation, and overreaction to minor occurrences.
- Be aware that students with eating disorders may respond to low intensity interactions with tears or withdrawal.
- Bulimia nervosa can be associated with a number of high risk behaviours such as substance abuse. It is important to recognize that these behaviours signal the distress the individual is experiencing and function as coping mechanisms for them.



If you suspect an eating disorder

If you suspect a student in your class may have an eating disorder but s/he has not been diagnosed, consider the following strategies:

- Let the student know you are concerned and there to help, while still respecting their need for autonomy and privacy
- **DO NOT** force the student to eat
- Observe, describe and document behaviours of concern across times and settings
- Find out where to go for support and encourage the student to seek it
- Consult with parents and the child on an information-sharing basis
- Refer to the school-based team for referral to other experienced professionals for a thorough assessment

Contacts

The Eating Disorder Resource Centre of British Columbia

St. Paul's Hospital
1081 Burrard Street
Vancouver, B.C. V6Z 1Y6
Tel: (604) 631-5313
Fax: (604) 631-5461
Toll-Free Line: 1-800-665-1822

B.C.'s Children's Hospital Eating Disorders Program Children's and Women's Health Centre British Columbia

4480 Oak Street
Vancouver, B.C. V6H 3V4
Tel: (604) 875-2200

BC Eating Disorders Association

526 Michigan
Victoria, B.C. V8V 1S2
Tel: (250) 383-2755

Canadian Association of Anorexia Nervosa and Associated Disorders
1099 – 2040 W. 12th Avenue
Vancouver, B.C. V6J 2G2
Tel: (604) 739-2070

National Eating Disorder Information Centre

200 Elizabeth St., College Wing 1-211,
Toronto, Ontario M5G 2C4
Tel: (416) 340-4156
Fax: (416) 340-4736

Eating Disorders Theme Page on CLN:

<http://www.cln.org/themes/eating.html>



For More Information

Contact health care professionals through your local Child Development Centre and/or public health unit.

Rett Syndrome

Rett syndrome is a neurological disorder, seen almost exclusively in females, which results in profound developmental disability. Most researchers now agree that Rett Syndrome is a developmental disorder rather than a progressive, degenerative disorder as once thought. While there is strong evidence of a genetic basis, the origin and cause of Rett Syndrome remain unknown. Barring illness or complications, survival into adulthood is expected. The prevalence rate in various countries is from 1:10,000 to 1:23,000 live female births.

Children with Rett syndrome usually show an early period of apparently normal or near normal development until six to 18 months of life. After the first few months of life, however, their development is characterized by a slowing of gross motor development, loss of communication skills and deterioration of fine motor skills. The most fundamental and severely handicapping aspect of Rett syndrome is Apraxia — which means the will to move is present, but the child is unable to carry through the movement. It can interfere with every body movement, including eye gaze and speech, making it difficult for the child with Rett syndrome to do what she wants to do.

Because children with Rett syndrome lose eye contact and facial expression, and their play becomes restricted to a few repetitive actions, their appearance and behaviour may be misdiagnosed as autistic. Rett syndrome is also often misdiagnosed as cerebral palsy or non-specific developmental delay. Early articles about Rett syndrome all described the girls as having severe intellectual retardation associated with communication malfunction, severely impaired speech, and severely impaired understanding of language. Current thought tends more to the 'not proven' verdict — while most of the children with Rett syndrome may have severely limited speech and movements, there is an increasing recognition that these external expressive problems are not necessarily a reliable measure of understanding or processing.

Current research looks for ways for the child to communicate and interact with their environment that do not require them to use their hands. Despite their difficulties, children with Rett syndrome can continue to learn and enjoy family and friends well into middle age and beyond. They experience a full range of emotions and show their engaging personalities as they take part in social, educational and recreational activities at home and in the community.

...while most of the children with Rett syndrome may have severely limited speech and movements, there is an increasing recognition that these external expressive problems are not necessarily a reliable measure of understanding or processing.

Recognizing the Child with Rett syndrome



Key

Behaviour Patterns

- Repetitive hand movements.
 - Severely impaired expressive language.
 - Breathing dysfunctions.
 - Decreased mobility with age.
 - An increase in unusual or difficult behaviours unusually indicates an increase in stress.
 - Difficulty with headaches, bright lights, noise, temperature, odours and/or worsening of pre-existing allergies.
- All children with Rett syndrome do not display all of these symptoms, and individual symptoms may vary in severity. A diagnosis by appropriately qualified medical personnel is needed to verify the condition. For example, the developmental/assessment team at Sunny Hill Hospital for Children, or B.C. Children's Hospital, or Queen Alexandra Hospital, or a pediatric neurologist or developmental pediatrician are able to diagnose this syndrome. Individuals display different combinations of the following observable symptoms:
- Period of apparently normal development until between six and 18 months.
 - Normal head circumference at birth followed by slowing of the rate of head growth with age (three months to four years).
 - Severely impaired expressive language and loss of purposeful hand skills, which combine to make assessment of receptive language and intelligence difficult.
 - Repetitive stereotyped hand movements including one or more of the following: hand washing, hand wringing, hand clapping, hand mouthing, which can become almost constant while awake.
 - Shakiness of the torso, which may also involve the limbs, particularly when upset or agitated.
 - If able to walk, walking may be unsteady, wide-based, stiff-legged gait or toe-walking.
 - Breathing dysfunctions which include breath holding or apnea, hyperventilation and air swallowing which may result in abdominal bloating and distension.
 - Seizures. For information on seizures, see *Epilepsy in Awareness of Chronic Health Conditions – July 1995*.
 - Muscle rigidity/spasticity/joint contractures which increase with age.
 - Scoliosis (curvature of the spine).
 - Teeth grinding (bruxism).
 - Small feet (in relationship to stature).
 - Growth retardation.
 - Decreased body fat and muscle mass, but a tendency toward obesity in some adults.
 - Abnormal sleep patterns and irritability or agitation.
 - Chewing and/or swallowing difficulties.
 - Poor circulation of the lower extremities, cold and bluish-red feet and legs.
 - Decreased mobility with age.
 - Constipation.

Classroom Strategies

- Meet with the parents and the child as early as possible in the school year to determine individual needs. Student records should reveal special programming in previous years/placements.
- Develop an Individual Education Plan (IEP) to include modified learning outcomes and essential and supportive skills.
- Consider the use of the Planning Alternative Tomorrows with Hope (PATH) process to develop a plan for the transition needs of a child with Rett syndrome. PATH is a simple but useful framework on which to hang other, more specific, plans for example an IEP.
- Consider placement on the basis of individual needs and program availability - help the parents choose the best alternatives. This may be a special class, a regular class, a combination of the two.
- Work with other professionals as a team to help the student lead a productive life. Include parents, occupational and physical therapists, health care professionals, speech language pathologists, and paraprofessionals.
- An increase in unusual or difficult behaviours probably indicates an increase in stress, sometimes a feeling of loss of control in a specific situation. Try saying, "Do you have something to tell me?" The individual may need to go to a quiet, less stimulating environment and/or "safe person".
- Talk to students about Rett syndrome, and if the child is comfortable with the situation, have the child or parent explain any adaptive needs. Encourage other students to find out how they can assist and when they should assist.
- Allow the child to experience natural consequences in the choices s/he makes.
- Encourage communication to prevent isolation. Always allow enough time for the child to take in information, and respond.
- Provide environments and situations that are strongly motivating in the least restrictive environment, taking into account each student's own special needs.



During a Partial Seizure

- No first aid is required.
- Protect the student from danger, but do not forcibly restrain.
- Do not give the student anything to drink.
- Gently talk to the student.
- Be comforting and helpful.

Steps of a PATH session:

1. Gather together everyone who is closely involved with the person.
2. Elect a facilitator and scribe to make a written and graphic record of the meeting.
3. As a group, look at and respond to the following questions:
4. Situate yourself in a very positive future, picture it clearly, then think backwards:
 - By the end of this planning period, what will we have?
 - Where am I/are we now?
 - Who can I enrol on this journey to help me with these things?
 - What are some ways I can build strength while I'm on this journey?
5. Chart actions for the next three months.
6. Plan the next month's work.
7. Commit to the first step (the next step).

The PATH planning process is described in detail in PATH, A Workbook for Planning Alternative Tomorrows with Hope, by J. Pearpoint, J. O'Brien and M. Forest, Inclusion Press, Toronto, (1993).

- Maintain a record of observations of responses to cause and effect, choice-making, following directions and recognition of objects and people.
- Closely involve the parents in the work and techniques used at school. The child will function better in a structure common to home and school.
- If not already established, work on the development of a reliable method for communicating yes/no in order for the student to be able to express choices. Some examples developed by students include:
 - a prolonged eye contact for yes, and gaze aversion for no;
 - a definite eyeblink;
 - making a fist, slightly held up;
 - a definite head nod;
 - an occasional verbal “yes”, leaning forward and pointing with the nose to a “yes/no” card held in front of the student’s face.
- Be aware of any specific medical assistance. For example, the child may be on oxygen and may require a trach to help breath. It is the responsibility of the parents to keep the school informed.
- Phrase questions simply, and allow time to respond. Use short sentences.
- Encourage communication by having the student express wants, rather than forming simple "yes" or "no" responses.
- Gain attention by using simple commands, for example, use eye contact. Be precise.
- Help the child focus on the task. Remove items that might distract.
- Expect appropriate behaviour. All students are accountable for their behaviour.
- Encourage interaction and involvement with other students through play and classroom activities.
- Help the student develop independence. This will both increase self-esteem and improve social relationships.
- Become familiar with alternative communication methods. Determine the type best suited to the individual to allow for active and fulfilling participation in everyday life. These can include:
 - eye-gaze response;
 - picture, letter and word boards;
 - touch or switch operated voice output devices (switch activated tape recorder, Big Mack switch, etc.);
 - preprogrammable augmentative communication devices.
- Guard against subtle influences when facilitating communication:
 - actually pushing the headpointer onto the keys, or pushing the keyboard onto the headpointer;
 - encouraging movement in the "right" direction rather than any other;
 - preventing hitting the "wrong" key for various reasons;
 - tensing the fingers of your hand in excitement as the student approaches the "right" key, which might give a clue to your thoughts.

Contacts

Canadian Rett Syndrome Resource Center

RR#1, South Mountain, Ontario K0E1W0

Tel/Fax: (613) 989-2851 (available 9 a.m. to 9 p.m. EST)

International Rett Syndrome Association

9121 Piscataway Road, Suite 2-B

Clinton, MX 20735

Tel: (301) 856-3334

1-800-818-RETT

Fax: (301) 856-3336

<http://www2.paltech.com/irsa/irsa.htm>

Sunny Hill Health Centre for Children

Development and Behaviour Program

3644 Slocan Street

Vancouver, B.C. V5M 3E8

Tel: (604) 434-1331

Fax: (604) 436-1743



For More Information

Contact health care professionals through your local Child Development Centre and/or public health unit.

Traumatic Brain Injury

Children with traumatic brain injury have experienced a trauma to the head caused by an external force that may result in impairment of cognitive abilities or physical, behavioural or emotional functioning. These impairments may be either temporary or permanent and may cause partial or total functional disability or psychosocial maladjustment. At the same time they leave the student no less interested in life, aspiring to, and in need of, the same opportunities as all of their peers.

Brain injury can be caused by any trauma to the head. Traumatic brain injury can occur accidentally. In young children, accidental falls and automobile accidents are the most frequent causes of traumatic brain injury. In adolescents, motor vehicle accidents, sports accidents and drug and alcohol involvement are the most frequent causes. Traumatic brain injury can also be the result of child abuse. Infants can sustain severe developmental and neurological damage, even death, when shaken.

Traumatic brain injury is a very complex phenomenon. The extent to which the child is adversely affected depends on the severity of injury. The most serious brain injuries result in a period of unconsciousness/coma. However, even head injuries that do not lead to coma can result in serious impairment for a child. Concussions and momentary loss of consciousness, while seemingly minor at the time can lead to long term problems. Compared to students with learning disabilities, students with traumatic brain injury often have more variability in abilities.

Of traumatic brain injury cases, 75 per cent are categorized as mild. At one time, little attention was given to individuals with mild injury. This is partly because in these cases no skull fractures and no abnormalities may appear during a neurological examination. Children with mild injuries, however, often have cognitive impairments that go undetected until difficulties occur in the classroom in the middle and upper elementary grades. Children with mild traumatic brain injury may experience a variety of problems, including: dizziness, headache, irritability, anxiety, blurred vision, insomnia, fatigue, distractibility, memory problems, manual dexterity, social comprehension difficulties, and perceptual motor slowing. These symptoms may dissipate over months or years, but may also have a permanent residual effect.

Children with moderate to severe traumatic brain injury will have more dramatic cognitive, speech/language, motor/sensory, and social/behavioural deficits, including disorientation or memory problems; information processing impairment; poor judgement and problem solving ability; speech and language deficits; lack of motor skills and stamina; difficulty with vision, hearing, and sense of smell; personality changes; and episodes of emotional instability. These may persist for months or years, or may be permanent. Either immediately following the injury or even years later, the child may experience seizures. For information on seizures, see *Epilepsy in Awareness of Chronic Health Conditions – July, 1995.*

Compared to students with learning disabilities, students with traumatic brain injury often have more variability in abilities.

Recovery from traumatic brain injury typically occurs rapidly in the first few months, particularly with motor functions and communication skills. Recovery of the higher cognitive functions related to attention, memory, and behaviour tends to occur more slowly. A gradual recovery of deficits usually occurs up to five years after the injury. As medical care continues to improve, allowing many of these children to survive their injuries, the implications for families and educators are significant in terms of the provision of long term educational and rehabilitative care. Early collaboration by professionals, including the classroom teacher, learning assistance teacher, OT/PT, speech and language pathologist, social worker, school psychologist or physician, will help develop a precise learning strategy for the student with traumatic brain injury. The teacher, the parent and the child (where appropriate) need to understand the child's neurological status and the strategy developed. Each student with traumatic brain injury presents his or her very own special needs. As no two students are identical, neither are any two brain injuries or the manner in which they occur. Educational programming that is integrated, interdisciplinary and individualized will ensure the opportunity for successful recovery is greatly enhanced for students with traumatic brain injury.

Recognizing the Child with Traumatic Brain Injury

Classroom teachers are often the first individuals to notice any changes in a child's ability to follow directions, complete projects, remember information, and get along with other students in the same setting. If a classroom teacher suspects a student may be demonstrating the effects of traumatic brain injury, a referral to the appropriate school-based team member should be made. Traumatic brain injury is a medical diagnosis. The following outline of the cognitive, speech and language, motor and sensory, and social/behavioural effects associated with traumatic brain injury is offered to help the teacher prepare for possible problems in the school environment.



| Classroom Difficulties | |
|-----------------------------------|--|
| Cognitive/Learning Effects | <ul style="list-style-type: none"> • Deficits in memory, attention, concentration, problem-solving and decision making • Difficulty with information retrieval and processing, planning, reasoning, organization • Overall slow performance • Decline in basic academic skills, including reading, comprehension, spelling, mathematics, language and vocabulary |
| Motor/Sensory Effects | <ul style="list-style-type: none"> • Visual and hearing acuity • Processing deficits • Difficulty with motor speed and eye-hand coordination, stamina, balance, spatial orientation, spasticity and involuntary movement, use of reflexes |
| Speech/Language Effects | <ul style="list-style-type: none"> • Motor and speech problems, including fluency disorders, word retrieval, comprehension of speech or written information and expressive language • Slow or rapid rate of speech • Difficulty processing facial features in communicating with others |
| Social/Behavioural Effects | <ul style="list-style-type: none"> • Association/reassociation with peers • Inappropriate social behaviour and understanding social rules • Low self-esteem • Limited self-control and age-appropriate behaviours • Withdrawal, depression, fatigue and irritability |

Classroom Strategies

If a student in your class has been diagnosed as having traumatic brain injury, consider the following strategies:

- Use a team approach with hospital or rehabilitation centre rehabilitation specialists to share information and discuss recommendations to ensure a smooth transition to school.
- Become familiar with the resources in your school and your community.
- Develop an Individual Education Plan (IEP) that includes transition goals and objectives, and that is concerned with all four domains: motor/sensory; cognitive; speech/language; and social/ behavioural. This will ensure an effective approach to learning.
- Set objectives that address long-term life goals as well as more immediate transition needs and review these plans frequently.
- Encourage the use of assistive devices, including computers, calculators, tape recorders, and other assistive learning devices.

Cognitive/Learning Needs:

- Teach the student the process of learning rather than teaching specific content: attending to each task, following simple directions, learning to shift from one task to another. When the student is doing well with the process of learning, content can be reintroduced.
- Provide direct instruction, where required, in strategies for goal-setting, self-monitoring, and problem-solving to complete tasks.
- Supplement oral instructions with visual reinforcement so the student can frequently check that s/he is following instructions. For example, write assignments on the board, photocopy instructions or use overheads.
- Combine the use of memory aids to strengthen information that needs to be remembered or to describe a situation that has occurred. These might include visualization, mnemonic devices, paraphrasing, retelling, role-play, and pantomime.
- Modify tests if necessary. For example, use untimed tests, provide extra time for tests, or divide the test into several parts to be completed at different times during the day.
- Teach the student to use cognitive behaviour modification. For example, have students repeat multi-step directions and listen to themselves before attempting a task. Other modifications might include cues; verbal rehearsal; self-questions; checklists; printed or pictured schedules of daily activities with locations and materials needed noted.
- Provide sequential instruction. Present part of a sequence and have students finish it.
- Place arrows or cue words, left to right, on the page to orient the student to space. Teach the student to use the cues systematically by scanning left to right.
- Have completed sample worksheets in a notebook to serve as models indicating how to proceed.
- If the student has difficulty taking notes, supply a copy of the notes from another student or from the teacher's notes.
- Provide a log book to record assignments or daily events.

- Encourage students to take thinking time before they respond to questions, to organize information by using categories (such as who, what, when, where), and to focus on one type of information at a time.
- Provide opportunities to participate in structured, collaborative groups.

Motor/Sensory Needs:

- Consider where the student with traumatic brain injury is seated. A seat in close to the teacher, and close to visual or auditory aids and instructional assistance, could assist the student in staying on task.
- Reduce course load.
- Have shortened school day if needed.
- Provide well placed rest periods or breaks to minimize the effects of mental fatigue or stamina problems.
- Have more difficult subjects scheduled earlier in the day when students are more alert.
- Allow extra time to get from room to room, and to complete tests.
- Have two sets of books: one at home and one at school so students don't have to carry them home.
- Label significant objects and areas. Provide name tags for staff.
- Use technology wherever possible and adapted equipment where needed.

Speech/Language Needs:

- Limit the amount of information presented. Give the student instructions in small units, in concrete terms, at a relatively slow pace. Pause for processing time and repetition if necessary.
- Describe visual instructional material in concrete terms, and provide longer viewing times or repeat viewings.
- Teach the student to ask for clarification or repetitions or for information to be given at a slower rate.
- Use pictures or written words in conjunction with auditory input to cue students.
- Pair manual signs, gestures, or pictures with verbal information.
- Use cognitive mapping strategies and age-appropriate language models.
- Check comprehension regularly and conduct frequent cumulative

Social/Behavioural Needs

- Develop an action team involving people who know the student to understand the student's problem behaviours and to organize a plan of support. The team may include yourself, another classroom teacher, a resource or integration support teacher, the vice-principal, a parent and/or a member of the school based team with behavioural expertise.
- Undertake a process of functional analysis of the communicative intent of the student to determine what behaviours are a problem, what contexts do and do not produce problem behaviours, and what effects the problem behaviours produce. Use this information to look for ways to make curriculum, scheduling and support changes, and to identify specific new skills that the student may learn and use in place of problem behaviours.



If brain injury is unknown

If a student in your class is displaying signs similar to traumatic brain injury, but s/he has not been diagnosed, consider the following strategies:

- Eliminate causal factors such as poor attendance, failure to understand instructions, understimulating environments, frequent family relocation, visual/hearing impairments, cultural and linguistic learning differences.
- Observe, describe and document behaviours across times and settings.
- Consult with parents and the child on an information-sharing basis to encourage involvement and understanding and to provide consistency in behaviour.
- Refer to the school-based team for referral to other professionals such as a school psychologist, family doctor or psychiatrist, for a thorough assessment

- Develop a self-management system in which the student monitors his/her own behaviour, self-awards points, and then approaches the teacher to get confirmation that the points have been earned.
- Plan for success. Break tasks into manageable sequential steps the student can handle, with frequent breaks which can be seen as rewards for appropriate behaviour.
- Provide printed or pictorial charts, schedules, or classroom maps that describe routines and rules of expected behaviours. Review these before each session and as needed throughout the day.
- Explore a variety of cueing systems, for example verbal cues, gestural cues or signs, that will remind or redirect the student to stay on task
- Develop a simple routine for asking for teacher assistance. Make asking for help a student goal and reinforce this heavily.
- Develop with the student a key word or phrase for the student to say when angry feelings begin.
- Employ “stop-action” technique. Immediately stop individuals from disrupting an activity, encourage them to verbalize an alternative behaviour, and have them follow through appropriately.
- Use a direct approach in addressing inappropriate behaviours, one that specifically informs the student about what to do or what not to do. For example, “John, you need to complete the first five problems of the worksheet before the recess bell.”
- Work with the student to develop social interaction skills. For example, interpreting non-verbal communication cues. Modelling and role playing along with reinforcement of appropriate skills tend to be most effective.
- Structure situations so that the student can practice perceiving the feelings of others or how to respond appropriately, such as using role plays where a teacher models how to interpret others behaviours.
- Begin activities by explaining the purpose of a lesson, reviewing printed or pictorial descriptions of how to do a task, and talking through several examples to help individuals get started.
- End activities by emphasizing to the student where they are in relation to the final steps of a task, and by encouraging students to observe the behaviour of others as tasks end.
- When transitions or unusual events are to occur, try to prepare the child for what is to come by explaining the situation and describing appropriate behaviour in advance.
- Give responsibilities that can be successfully carried out to help them feel needed and worthwhile.
- Remove unnecessary distractions from the classroom and offer a screened corner to your class as an earned privilege during scheduled times rather than a punishment. This avoids segregating the child who may need the screened corner to reduce distractions.
- Try a variety of teaching strategies including assigning a peer buddy, cooperative learning practices, development of class meetings, and life-space interviewing.
- Closely monitor time of day, medications and fatigue factors. Confer with physicians to determine the feasibility of adjusting medication times so as to not conflict with instructional times.



Contacts

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For More Information

Contact health care professionals through your local Child Development Centre and/or public health unit.

Williams Syndrome

Williams syndrome is a rare genetic disorder which impacts several areas of development including cognitive, behavioural and motor areas. It occurs in 1:20,000 births, and is caused by a single changed gene, not of any fault of either parent. In most families, the child with Williams syndrome is the only one to have the condition. This individual, however, has a 50 per cent chance of passing the disorder on to each of his or her children. Although intellectual disability is common among children with Williams syndrome, some individuals have normal intelligence.

Children with Williams syndrome are predisposed to certain medical and learning difficulties. Some children have few or no associated medical problems. For others, medical difficulties may include:

- birth defects, such as crossed eyes and hernias;
- heart problems, such as a narrowing of the aorta above the valve or a narrowing of the pulmonary arteries;
- high blood pressure; and
- hearing sensitivity which makes certain frequencies or noise levels painful and/or startling to the child.

Many children with Williams syndrome, especially younger children, are very sensitive to certain sounds and find it extremely difficult to concentrate with these sounds in the environment. Some are simply extra sensitive to all sounds, while others are sensitive only to specific sounds, for example, school bells or alarms.

All children with Williams syndrome have some difficulties with cognitive functioning, especially in the visual/motor integration area. There is, however, a wide range in the degree of these difficulties. They are often characterized by difficulty modulating emotions, poor fine motor coordination, and poor spatial, quantitative, and reasoning abilities. Young children with Williams syndrome often experience developmental delays. Older children often demonstrate distractibility and problems with attention. Some children have developed certain favourite topics that they like to talk about at any opportunity. These topics often involve something that has initially caused the child some anxiety, such as a noise-based topic (e.g., trains, fire engines, machines), or a “body based” topic (e.g., bones, medical procedures, etc.). Most children with Williams syndrome have substantial difficulties with tasks involving rapid movement and even more difficulty when visual motor integration is required.

On the other hand, many children with Williams syndrome have particular strengths in some areas. Some have an excellent ability to perceive subtle changes in the mood of an adult, good visual memory for people and places, and particularly good auditory memory and expressive language skills. They also have a love of language for language sake, appreciating the sheer beauty of sounds, words and sentences, especially unusual words or songs and phrases. Many individuals with Williams syndrome have a high degree of engagement with and connectedness to music. Children with Williams syndrome are often endearing. They are typically unafraid of strangers and show a greater

Although intellectual disability is common among children with Williams syndrome, some individuals have normal intelligence.

interest in contact with adults than with their peers, due to difficulty in forming relationships with peers. Most children are highly sociable and generally want to interact with and will be motivated to please the teacher. What they bring to the classroom is an important contribution: their bright eyes, engaging smiles, politeness, enthusiasm, and sense of the dramatic.

Recognizing the Child with Williams Syndrome

Individuals may display the following observable characteristics. A diagnosis by appropriately qualified medical personnel is needed to verify the condition.

- “pixie-like” facial features,
- small upturned nose,
- puffiness around the eyes,
- star shaped pattern in the iris,
- depressed nasal bridge,
- full lips and cheeks,
- small, widely spaced teeth,
- small chin,
- broad magnetic smile,
- sloping shoulders and protruding abdomen,
- distinguishable gait,
- low/poor muscle tone,
- increased range of motion in joints,
- joint stiffness becomes more common with age,
- poor movement control, and/or
- crouched posture.

Many children with Williams syndrome will have most of these, as well as many other features, but they will vary from person to person. The only feature common to all is some degree of learning disability.

Classroom Strategies

- Prior to enrolment, meet with the parents and the student to help determine how best to meet the individual needs of the student. Consider the emotional, physical, communication, learning, daily living, behavioural and social needs of the student.
- Consider educational program on the basis of individual needs and available support services.
- Consider the use of the Planning Alternative Tomorrows with Hope (PATH) process to develop a plan for the transition needs of a child with Williams syndrome. PATH is a simple but useful framework on which to hang other, more specific, plans for example an IEP.
- Develop an Individual Education Plan (IEP).
- Maintain ongoing communication with other members of the team: these may include paraprofessionals and health care professionals, including speech/language pathologists, hearing therapists, occupational therapists, physiotherapists, psychologists.
- Be aware of any specific medical problems or medication. It is the responsibility of the parents to keep the school informed of any changes.
- Encourage the use of assistive devices, including computers, calculators, tape recorders, and other assistive learning devices. The computer, in particular, can serve as a compensatory tool in the classroom.
- Be aware of the available specialized computer software especially designed to facilitate reading and communication.
- Give more time to complete tasks, break up tasks into small steps; use short blocks of time.
- Avoid the abstract in favour of the concrete and the visual.
- Gain attention by using simple commands, e.g., use eye contact or visual cueing with hands.
- Supplement visual stimulation with auditory stimulation.
- Help the child focus on the task - remove items that might distract, limit movement from one teacher to another.
- Use music to understand classroom routines and basic concepts, and as a language stimulation activity. Williams syndrome children are very musical and can learn many things through music.
- Use a phonetic and linguistic approach to reading instead of a whole word sight reading approach.
- Use social communication groups to focus on verbal reasoning skills and basic pragmatic communications.

- Provide a predictable schedule and routine with specific warnings marking daily transitions. For example, put on some music a few minutes before cleanup time.
- Expect appropriate behaviour. All students are accountable for their behaviour.
- Develop a model of behaviour management and social skills training which is compatible with both the home and classroom environment, and which is clear in its expectations, e.g., consequences, rewards.
- Through continuing communication between home and school, ensure consistency of behaviour and expectations and understanding on setbacks and successes.
- Remove unnecessary distractions from the classroom and offer a screened corner to your class as an earned privilege during scheduled times rather than a punishment. This avoids segregating the child who may need the screened corner to reduce distractions.
- Provide warning just before predictable noises when possible (fire drills, hourly bells, etc.) and minimize the opportunity for unpredictable noises.
- Allow the child to view and possibly initiate the source of bothersome noises. For example, turn the fan on an off or locate the fire alarm.
- Make tape recordings of the sounds and encourage the child to experiment with the recording.
- Following a medical assessment, include the student in physical activities.
- Help the student and others understand Williams syndrome. Initiate open discussion, considering individual differences and wide variations of abilities. Your own behaviour and acceptance will serve as a model.
- Help the student develop independence. This will increase self-esteem and improve social relationships. Use stories and role play/pretend play to deal with various anxiety provoking situations with student.
- Some children with Williams syndrome have favourite topics that they want to talk about more often than is socially appropriate. Use role play, stories, discussion and small group experiences to teach alternative appropriate topics, and to expand the child's repertoire.

Steps of a PATH session:

8. Gather together everyone who is closely involved with the person.
9. Elect a facilitator and scribe to make a written and graphic record of the meeting.
10. As a group, look at and respond to the following questions:
11. Situate yourself in a very positive future, picture it clearly, then think backwards:
 - By the end of this planning period, what will we have?
 - Where am I/are we now?
 - Who can I enrol on this journey to help me with these things?
 - What are some ways I can build strength while I'm on this journey?
12. Chart actions for the next three months.
13. Plan the next month's work.
14. Commit to the first step (the next step).

The PATH planning process is described in detail in PATH, A Workbook for Planning Alternative Tomorrows with Hope, by J. Pearpoint, J. O'Brien and M. Forest, Inclusion Press, Toronto, (1993).

- Present verbal instruction in concise single steps to reduce the language load and encourage the child to request clarification or repetition of information when needed.
- Encourage the development of a variety of relationships for friendship building, including older or younger children and children with or without special needs.

Contacts



For More Information

Contact health care professionals through your local Child Development Centre and/or public health unit.

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How to improve this resource book

We hope that this Resource Guide addresses most of your initial questions and concerns regarding providing appropriate programs for students with special needs. Since the users of any resource are often the ones best able to identify its strengths and weaknesses, let us know how this document can be improved. When the resource book fails to assist, or if you have any suggestions and comments, please complete a copy of this page and send it to the Special Programs Branch of the Ministry of Education.

How do you rate Awareness of Students with Diverse Learning Needs, What the Teacher Needs to Know – Volume 2?

| | Yes | No | If no, please explain: |
|------------------------|--------------------------|--------------------------|------------------------|
| 1. Useful? | <input type="checkbox"/> | <input type="checkbox"/> | <hr/> <hr/> <hr/> |
| 2. Easy to understand? | <input type="checkbox"/> | <input type="checkbox"/> | <hr/> <hr/> <hr/> |
| 3. Well organized? | <input type="checkbox"/> | <input type="checkbox"/> | <hr/> <hr/> <hr/> |
| 4. Complete? | <input type="checkbox"/> | <input type="checkbox"/> | <hr/> <hr/> <hr/> |

Other Comments:

Return to: Coordinator, Awareness of Chronic Health Conditions
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