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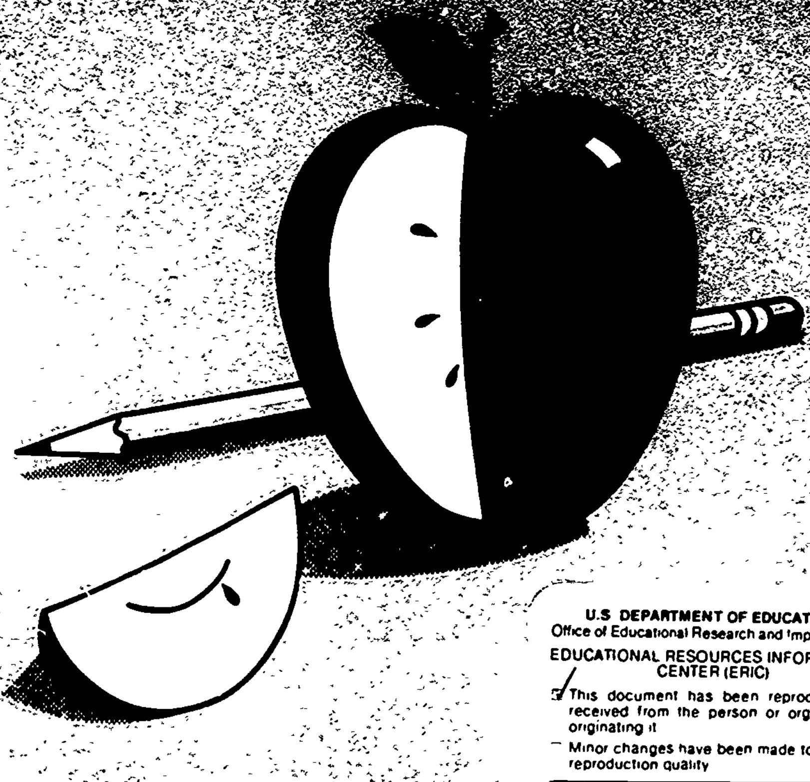
ABSTRACT

Intended for teachers, the booklet provides information on managing a child with cancer in the classroom. Sections deal with the following topics: cancer in the young and its treatment, effects of the disease and treatment, school reentry, the teacher's role, what to find out, dealing with parents, what to do, the student in the classroom, classmates, keeping in touch, other medical concerns, special concerns of junior and senior high school students, and terminal illness. Sources of additional information include self-help groups, a toll free cancer information service, a selected bibliography for educators, and a selected bibliography for young people. (DB)



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Public Health Service
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STUDENTS WITH CANCER

A Resource for the Educator

Produced by the
NATIONAL CANCER INSTITUTE
in cooperation with
WASHINGTON, D.C. METROPOLITAN CANDLELIGHTERS
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Contents

Introduction

At some point in your career as an educator, you may have a young person with cancer in your classroom or school. You may be concerned about the effects of this disease on the young person and the ways you can help. Depending on your prior experiences with cancer, you may be apprehensive about your own ability to handle your student's illness. You may, understandably, know little about cancer in the young and wonder what to do or say.

This booklet has been prepared to answer some of your questions and to indicate other sources of information and support. It will help you contact others who are close to your student to facilitate the young person's continued education.

What follows are explanations of the disease, its treatment and effects; suggested approaches for dealing with the young person, classmates, and parents; guidelines for school reentry; and referral to additional materials and organizations.

Much of this material is purposefully general. Medical explanations, for instance, are not detailed because there are many types of cancer in the young, and wide variations in response to treatment for each individual. Approaches to your student will also depend on the facilities and philosophy of the school, different teaching styles, and preferences of the parents and student.

In any case, you will undoubtedly need more specific information on the student's situation. With parental permission, school personnel can establish contact with caregivers who can further explain the young person's medical condition and answer other questions as they arise. Members of the health care team may be available on a continuing basis to assist you with any other concerns. Parents and, in some cases, the student can keep you informed. Another important resource is the school nurse, who can also act as a liaison.

Outlook

Today the young person with cancer stands a good chance of surviving the disease. Long-term survival rates for several childhood cancers are well in excess of 50 percent. Advances in all types of treatment, including surgery, radiation therapy (cobalt or X-ray) and chemotherapy (anticancer drug therapy), have produced dramatic increases in survival rates.

Despite the outcome of the disease, it is important to pay attention to the quality of the young person's life. Despite a serious illness, your student is still growing and developing and has the same educational and social needs as his peers.

Cancer In The Young And Its Treatment

Cancer is actually a group of diseases, each with its own name, its own treatment, and its own chances for control or cure. It occurs when abnormal cells begin to multiply and grow uncontrollably, crowding out the normal cells.

Leukemias (cancers of the blood-producing tissues), lymphomas (cancers of the lymphatic system, the network carrying fluid that bathes body cells and is important in the body's defense against disease), and brain tumors account for a large proportion of all cancers in young people. Solid tumors (e.g., bone) affecting other parts of the body such as arms or legs constitute most of the remainder of cancers occurring in young persons.

Early diagnosis is often difficult because many cancer symptoms mimic those of other illnesses. If cancer is suspected, many pediatricians or general practitioners refer the young person to a medical center which has teams of cancer specialists who confirm the diagnosis and design a specific treatment plan. If the family lives some distance from the center, the local physician often administers medicines and participates in care. Periodically the young person returns to the cancer center for reevaluation.

The goal of treatment is to remove or destroy the abnormal cells by surgery, radiation, or chemotherapy (anticancer drug therapy), or some combination of these methods. Initial treatment may be intense and then may become more moderate depending upon the young person's response. It may be necessary to continue some form of treatment for many years.

Remission and relapse (or recurrence) are terms used to describe different phases of the disease. A patient is in remission when no evidence of cancer is detectable. Relapse refers to the return of the disease after apparent improvement or a period of remission. Following relapse, the young person again undergoes treatment in an attempt to bring about remission. Although increasing numbers of young people are maintaining their initial remissions, others go through several cycles of remission and relapse. Some respond to treatment but do not attain a state of complete remission. Failure to control a relapse often results in progression of the disease and eventual death. However, if a complete remission continues for a number of years, the patient's doctor may begin to think of the young person as "cured."

Effects Of The Disease And Treatment

Both the disease and treatment can produce physical changes in the patient such as nausea, vomiting, and fatigue, which decrease energy levels and the ability to participate in school activities. Other possible changes, which are usually temporary, include weight gain or loss, mood swings, facial fullness and distortion, problems with coordination, difficulties with fine and gross motor control, body marks resembling tattooes which identify sites of radiation therapy, and muscle weakness. Patients with solid tumors may have surgical changes, such as amputation or scars.

Hair loss occurs in many patients undergoing chemotherapy and is, perhaps, to them the most disturbing aspect of their treatment. The hair may fall out suddenly or over a period of weeks or months. It may grow back while the patient is still receiving therapy, but doesn't usually return to normal until after chemotherapy is completed. The young person will often wear a wig, hat, or scarf to hide the loss.

Any of these physical changes can result in teasing and rejection by peers and can create a reluctance to resume friendships and return to school.

Young people with cancer also must face emotional challenges. They fear relapse and the subsequent repetition of treatments. Emotional energy usually spent mastering basic developmental skills now is used to cope with the illness. For example, teenagers have difficulty attaining the independence so important to their development when the disease forces them to be dependent on parents and caregivers. In addition, the young person must learn to deal with others who treat them differently because of their disease; they may subsequently seem to withdraw, regress, or become belligerent.

School Reentry

Young people with cancer can benefit from attending school throughout their illness. They feel better if they are productive in the role of learner, gaining the satisfaction that academic achievement brings.

Frequent absences for medical reasons, overprotection and/or overindulgence by parents, limitations on physical activity, and social isolation tend to be common obstacles to regular school attendance. But these obstacles are not insurmountable. Successful reentry is possible given strong family reinforcement and positive support from educators and caregivers.

The Teacher

Planning for the student's return to class may cause you to address your feelings about life-threatening illness. You might find it helpful to share your concerns with a physician, social worker, or nurse from the student's treatment center. In your own school, assistance can be provided by the school nurse, counselor, or an educator who has taught young people with cancer or other chronic illnesses. These professionals may also be able to suggest classes to attend and helpful literature.

Still, no matter how prepared you are, having a student with cancer in the classroom can be emotionally demanding and time-consuming. There may be times when you feel unequal to the task or depressed about your student's situation. At these times, it may help to know that health professionals who work with young patients also are subject to these same emotions and rely on each other and outside sources for support.

Just as caregivers do, you should remind yourself that you're part of a team which includes parents, treatment center personnel, and other school staff members. Whether you are working through your own feelings, looking for advice, or sharing loss, support and guidance should be available from others on your team.

What To Find Out

When planning for the student's return, it is important to gather information about the young person's situation. You should contact parents and treatment center staff (if available) to find out:

- ☐ Specific type of cancer and how it is being treated;
- ☐ When treatment is administered, what potential side effects are, and effects on appearance and behavior;
- ☐ Approximate schedule of upcoming treatment, procedures, or tests that may result in the student's absence from the classroom;

☐ Limitations, if any, on the student's activities (Periodic updates from parents are also helpful.);

☐ What the student knows about the illness (Although current policy is to be honest with young people who have cancer, there are exceptions.);

☐ For younger students, what the family would like classmates and school staff members to know;

☐ For adolescents, whether the student wishes to talk directly with teachers about any of the above points.

Dealing With Parents

When talking with parents, usually a sympathetic but direct approach is best. Most parents want teachers to ask about their child and the disease and are willing to supply information. Also, remember that if they are angry or sad (even to the point of tears), these feelings are not necessarily caused by or directed to you.

If parents are depressed, hostile, or overly anxious, a united approach by school and health professionals can be reassuring. Treatment center psychologists and outreach professionals can suggest additional strategies appropriate to the situation.

What To Do

Once the information about the situation has been obtained, planning can proceed. If the treatment center is close, doctors, nurses, or social workers, along with school personnel and parents, can meet to prepare a joint plan. Even if including caregivers is not possible, a *consistent* plan or approach should be developed at a meeting of school personnel including:

☐ Designating one teacher, counselor, administrator, or school nurse as the liaison between the school, the student's family, and the treatment center. Whatever the choice, the liaison person should have the time and be willing to assume the responsibility for keeping *all* the young person's teachers and teachers of siblings informed.

This is especially important for junior and senior high school students, who come in daily contact with several teachers, all of whom should have accurate information on the student's condition. Another means of ensuring information dissemination is to arrange a meeting at the beginning of each semester between a member of the medical staff and all teachers of the junior or senior high school student. The family and student, of course, should give consent for the meeting and ideally can also be involved.

☐ Asking the principal and counselor to assist with special needs, such as transportation. Young people with cancer also may need places to rest, have snacks, or be by themselves for a while.

The Student In The Classroom

Students with cancer should be accepted as young people with a chronic disease who require periodic treatment. If the cancer is ignored, a major part of the young person's life is overlooked. On the other hand, if the cancer is an overwhelming concern, other important aspects of the young person's life may be neglected. Although some concessions may be necessary, a balance must be struck between what students can reasonably do and what they *must* do to maintain their self-image.

Like their peers, young people with cancer need love, support, and understanding. But they should not be overprotected: the same limits on behavior apply to students with cancer as to their classmates. Teachers should discipline and hold reasonable academic expectations for young patients. Doing less will rob them of pride in learning and accomplishment and will prevent camaraderie with their peers. Obvious special treatment will create resentment among classmates and can be devastating to the student with cancer. For example, assignment deadlines may need to be correlated with a student's treatment schedule. However, the completed work should be evaluated by the same criteria used for the rest of the class.

Teachers should also be alert to any new learning or behavioral problems (peer fighting, hostility, irritability), which should be brought to the attention of the person acting as liaison between the school, family, and treatment center.

It is also important for students with cancer to feel a part of their class, even if absences for medical reasons preclude full-time attendance. You should consider sending assignments to the young person at home or to the hospital; many medical centers have programs for students to continue schoolwork. Other approaches can be used, depending on the school and the situation, including attending school for part of the day or being tutored.

Classmates

The parents of the young person with cancer and the student should be consulted before you discuss the illness with class members. Some school districts also require prior written permission from the parents of each class member. The content and manner of conducting discussions will vary according to students' ages, preferences of the parents and the student with cancer, and your wishes.

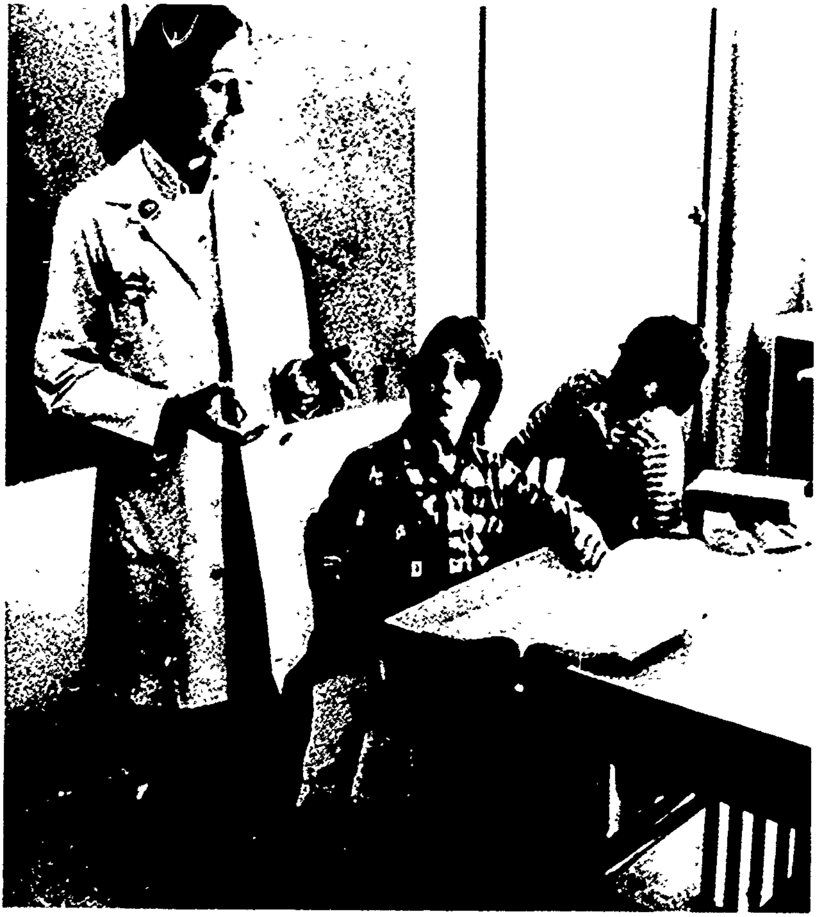
The following suggestions from educators who have taught students with cancer may be useful:

- ☐ Begin by asking students in the class how they want to be treated when they are ill or how they feel when they are around someone (of any age) who is sick. Use answers to these questions as bases for discussing how classmates might treat their friend with cancer.
- ☐ Explain to classmates the type of cancer their friend has, the kind of treatment received, and the ways the disease and treatment may affect the student's appearance and/or behavior. This is particularly useful in dealing with embarrassing side effects such as temporary weight gain or hair loss. Classmates who know that these changes come about

because of the lifesaving therapy their friend is receiving are less likely to tease and may even defend the student against the ill-considered remarks of outsiders. Also, reassure classmates that they can't "catch" cancer and emphasize that no one knows what causes it.

☐ Prepare a health or science unit for the study of cancer. Assign groups of class members to develop research reports on a specific type of cancer treatment and side effects, making sure that source material is up-to-date. When completed reports are shared with the class, students will have basic knowledge about cancer as well as their classmate's disease.

☐ Invite personnel from the treatment center or another organization (one teacher involved the social worker from the local American Cancer Society office) to make a presentation to the class. This approach should be a supplement, rather than substitute, for class discussion led by the teacher.



Classmates are sure to have questions and be concerned about their friend at other times during the illness. Most young people with cancer prefer answering questions directly rather than having to deal with mute stares or turning away.

If teasing occurs, find out if classmates feel the student with cancer gets unfair attention, pampering, or special consideration beyond what is really necessary. Are they frightened and putting distance between themselves and the student as a defense? Are they normally aggressive? Through stories, discussion, and role playing, you can help teasers understand their own motives and discover more desirable ways of coping with the situation and the feelings which give rise to teasing.

Keeping In Touch

Prolonged, unexplained absences of the young person with cancer may be anxiety-provoking for other students. Encourage classmates to write to their friend and, if it is convenient for the parents and the student with cancer, a few classmates might plan a visit. Whatever the arrangements, it is vital for the young person with cancer to feel part of the class. In the words of one teacher:

> My student was present in my classroom only 36 days of the school year due to cancer and subsequent breakages of his leg. However, he was a class member *every* day. My students wrote him every other week. We sent Halloween candy, Christmas cards, Valentines, birthday cards and get-well cards. We visited him at home (as a class) which his parents wanted. It made his later return to school much easier. I encouraged telephone calls by students and refused to let the children forget him.

Other Medical Concerns

You may have other health-related concerns about the student with cancer. The most common are:

Activities. In general, young people with cancer should be encouraged to undertake all activities suited to their age. Most set a pace that is comfortable for them and do not have to be cautioned against overexertion. Do not assume what the patient can or cannot do. Through the school liaison, maintain contact with the parents and treatment center concerning special limitations.

Infections. No special precautions are necessary with the following three exceptions: shingles (herpes zoster), chickenpox, and regular measles. Actual or suspected exposures *must* be reported immediately to the parents and treatment center, because young people on chemotherapy are especially vulnerable to these diseases. It may be possible to take measures that will prevent serious complications if the exposure is reported immediately. Sibling exposure to these diseases *must* also be reported to the parents *without delay.*

Medical Crises. It is unusual for the young person with cancer to have a medical crisis in the classroom. Ask the parents or school or hospital liaison if there are any potential medical problems. Treat minor medical problems (e.g., nausea, headaches) as you would for any other student. However, if these problems persist, they should receive medical attention.

Health Screening. The student with cancer is subject to the same health concerns and maladies of any other young person and requires routine health screening. For example, vision and hearing tests are necessary on a routine basis just as they are for other young people.

Communicability of Cancer. Cancer is not contagious. In this respect, consider your student as someone recovering from a broken bone rather than having a cold or the flu.

Special Concerns Of Junior And Senior High School Students

In some ways, the experiences and needs of adolescents with cancer differ from those of younger students. These differences reflect the developmental issues facing adolescents (i.e., independence, peer acceptance, body image, and self-worth), as well as the mechanics of secondary as opposed to elementary schools.

Cancer often interferes with the adolescent's attempts to achieve independence from parents and other adults. The illness and treatment many involve limitation of activites and temporarily place the adolescent in the position of being cared for like a younger child. Since the parents fear losing the young person to cancer, they may tighten their control even more, leading to inevitable conflict. If you notice or suspect this situation with your student, counseling from the medical center or school can help open lines of communication. Once the dynamics of the situation are understood by parents, counselors can assist all concerned to allow the student

more freedom of choice in school and home life.

At a time when peer pressure assumes vital importance, the adolescent with cancer is quickly classified as "different," both by the fact of the illness and by any visible manifestations of treatment, such as hair loss or weight gain. Also, certain types of cancer are more common among adolescents than young children, and treatment results in obvious body changes. For example, adolescents are more likely to develop a bone tumor requiring amputation and a lengthy rehabilitation process. Physical limitations can interfere with participation in sports and other school activities, creating a sense of isolation. Teasing or rejection by peers can result in varying degrees of withdrawal from extracurricular activities, or even from school. You can help by encouraging the young person's participation wherever possible in social activities that foster peer acceptance. If you are aware of problems with other students, you can intercede to try to resolve the conflict. Simple solutions will not always be readily apparent or even workable. If, for example, the student was a "loner" before diagnosis, encouraging acceptance by classmates becomes very difficult.

The size and complexity of junior and senior high schools also influence the student's ability to reenter school successfully. Secondary students must deal with many teachers, some of whom are new each quarter or semester and may have no information about the illness and treatment.

Teachers cannot easily inform all students in the school of the young person's illness. Although immediate classmates may be understanding and supportive, ridicule can come from students in other classes or grade levels.

Policies necessary to the operation of a large school can create problems for the young person if communication is poor and special arrangements are not made. For instance, rules against wearing hats in class may create embarassment for the student without hair, when a teacher who is unaware of the illness demands that the hat be removed. Schedule changes, necessary for medical care, can sometimes be difficult to arrange. Although physical education requirements may be waived completely, it is often difficult for faculty members to allow the student limited participation or alternatives to active involvement.

The larger classes and greater number of teachers may make it more difficult for the young person to maintain contact with the school during periods of extended absence. This can lead to a reluctance on the student's part to return to school when well again for fear of social awkwardness and difficulty in "catching up."

For students with motor problems (weakness, impaired coordination, or leg amputation), the size and structure of the school building may pose problems in arriving at classes on time.

Part of the solution to many of these problems is communication. As previously mentioned, one person in the school should be made responsible for contact with the student's medical staff and for disseminating information to all teachers involved with the student.

Ongoing contact between medical staff, faculty representative, and other faculty members is essential throughout the year, especially at the beginning of semesters and when the student's medical condition changes, e.g., when complications from treatment, relapse, or secondary illness occurs.

A single individual who has rapport with the young person should meet frequently with the student to discuss academic progress and social interaction. Other teachers should become aware that this individual is the "trouble shooter" to whom problems concerning the young person should be referred.

Terminal Illness

Despite improvements in survival rates, cancer in some patients cannot be controlled and is ultimately fatal. This raises the questions of how to manage the terminally ill student in the classroom during the later stages of the illness and how to respond to parents and classmates after death. Even in the final phase of illness, school can remain a rewarding experience for the young person. Often simple measures can help the student get the most from life remaining. For example, those who become too fatigued to attend school for a full day can often benefit from half-days or even an hour's attendance each day. As energy ebbs, assigned work should be adjusted accordingly. The young person who has lost a great deal of weight may be uncomfortable sitting in a wooden desk-chair, but may do quite well if allowed a pillow or two to sit on.

When a student dies, classmates may express their grief in a bewildering variety of ways. Some are quite open, while others may appear almost indifferent to the loss of their classmate. Such responses are a normal variation in the gamut of young people's grief reactions. They may assimilate the information about a death gradually, as they become able to deal with the event and its implications. Feelings of loss for the young person with cancer should be acknowledged, but no attempt should be made to force classmates to talk about the death or to deal with grief before they are ready. Most young people do so in their own way and at their own pace, if they are allowed but not forced or hurried.

Attending the memorial service or funeral of the student is another way of helping classmates understand the meaning of the death. For very young children, especially if they have not seen their sick friend for a long time, the service may help them realize that death is irreversible. In addition, it provides an opportunity for saying a last goodbye and for expressing sorrow for the loss of a friend. This is not to say that every friend or classmate should attend the service. The decision to do so rests with each individual and with each student's parents. No young person should be forced to go to the service.

As in the period of the student's illness, classmates are likely to have many questions after death. Again, most are best able to cope with this distressing event if they are given honest, simple, straightforward answers to their questions. Classmates may also want to create a memorial to their friend, such as a tree to be planted on the school grounds or some piece of equipment to be donated to the school. Organizing such a project and raising funds for it can be a valuable experience for classmates as well as provide the parents, brothers, and sisters of the young person with tangible and usually greatly appreciated evidence of the extent to which others share their feelings of loss.

Conclusion

Educators who have worked closely with young patients have found the experience rewarding and enriching. Working with the family and health care team, educators can maintain and improve the quality of life for the student. In turn, young people with cancer have much to teach those around them. Their sharpened sense of values and purpose is thought-provoking for peers and educators alike. The courage and strength they display while coping with the illness affirm the richness of life and learning.

Additional Information

Progress and developments in cancer in the young have been so rapid that information printed before the mid-1970's is often outdated and generally more pessimistic than current information. Local chapters of the American Cancer Society and the Leukemia Society of America have materials on pediatric cancers that are available free of charge. Additional sources of information include:

CANDLELIGHTERS FOUNDATION
2025 Eye Street, N.W., Suite 1011
Washington, D.C. 20006

A mutual support and self-help group of parents of children with cancer dedicated to improved communications, information, and treatment. Bibliographies of materials on death and dying are available fr[illegible] charge for children and teachers of young people with cancer.

Cancer Information Service

The National Cancer Institute sponsors a toll-free Cancer Information Service (CIS), open 7 days a week to help you. By dialing

1-800-4-CANCER

(1-800-422-6237), you will be connected to a CIS office, where a trained staff member can answer your questions and listen to your concerns.

In Alaska, call 1-800-638-6070; in Hawaii, on Oahu call 524-1234 (on neighboring islands, call collect).

Spanish-speaking staff members are available to callers from the following areas (daytime hours only): California, Florida, Georgia, Illinois, northern New Jersey, New York, and Texas.

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Selected Bibliography For Young People

The titles listed below include true-life as well as fictional stories and books. They are listed here because they are representative of available materials of potential interest to children with cancer. Your local library or bookstore should be able to get these books for you.

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Gravelle, Karen and Bertram A. John. *Teenagers Face to Face with Cancer.* New York: Julian Messner, 1986. (Ages 12+).

Howe, James. *The Hospital Book.* New York: Crown, 1981. (Ages 6 – 12).

Hyde, Margaret O. and Lawrence E. Hyde. *Cancer in the Young: A Sense of Hope.* Philadelphia: Westminster, 1985. (Ages 10 – 16).

Lancaster, Matthew. *Hang tough!* New York: Paulist Press, 1983. (Ages 8 – 12).

Silverstein, Alvin and Virginia Silverstein. *Cancer.* New York: Harper and Row, 1977. (Ages 8+).

Simonides, Carol. *I'll Never Walk Alone.* New York: Continuum, 1983. (Ages 14+).

Swenson, Judy H. and Roxanne B. Kunz. *Cancer: The Whispered Word.* Minneapolis: Dillon, 1985. (Ages 7+).

Books for Friends

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On the Death of a Friend or Sibling

Bernstein, Joanne E. *Loss: And How to Cope with It.* New York: Clarion, 1981. Ages 10+).

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