...because kids can't fight cancer alone!

Candlelighters™
Childhood Cancer Foundation

FALL 2001 **The Quarterly Newsletter**

Included in the Next Edition of "The Quarterly"

Dr. Brian Druker reports on STI-571 (article delayed)

Calcium & Bones

Now available on Candlelighters website:

Current list of COG treatment centers

Current events Calendar

Candlelighters' "Candlewear"

Awareness Stamp Information

Inside this issue:

National Childhood Cancer Awareness Holiday Tree 2001 Goes "Virtual!"

Help us surpass last year's 2,000 gold ribbons. Register your child's name on our web-based holiday "e-tree!"

Gold ribbons can be purchased in honor or memory of children who have or have had cancer on our website for $5.00 each.

ALL gold ribbons will be returned to the address requested during the time of registration.

Web Lighting Ceremony
www.candlelighters.org
Date: Friday Dec. 21st
Time: TBA

Light Up The Holidays With Hope 2001

Please stand united with childhood cancer families across the U.S., as we honor our children, and build awareness of the impact that cancer has upon the lives of thousands of children each year!

To register, go to: www.candlelighters.org
Click on the Awareness "e-Tree" logo

From Our Director's Desk

By Ruth Hoffman

Candlelighters joins with fellow Americans, in empathetic support of the tragic loss of life as a result of the September 11th terrorist attacks on our country. We stand united to mourn this loss, while heeding our President's directive to not succumb to the paralyzing threats that the terrorists wished to impose upon us as a nation. In doing so, Candlelighters continues to provide services to thousands of childhood cancer families. Sadly, cancer does not become paralyzed as a disease during these days of uncertainty. In fact, each and every school day 46 children continue to be diagnosed with this life threatening illness. Greater than 12,400 children this year will join the thousands of survivors and children currently receiving cancer treatment, as they face the battle of their lives – the battle to beat this devastating disease. One third of these children will lose that battle.

We wish to thank so many of you who expressed concern for our safety, given our national office's proximity to D.C. and our policy related activities on Capitol Hill. We also extend our sincere sympathy to those of you whose lives were directly impacted by this great tragedy.

Many people have inquired about the second **Childhood Cancer Awareness Holiday Tree** in Washington DC. While we were well underway in the planning (hand made quilts to distribute to cancer children attending, Starlight bears for all kids attending, tree donated, ribbon purchased, government and celebrity involvement), sadly we have been unable to make alternative location arrangements for this year. Specifically, the September 11th attacks made it impossible to use a Federal building for the awareness tree lighting event, due to the need for massively increased security. This, in combination with the on-going anthrax incidents in the D.C. area, its impact on Candlelighters' mail delivery and our concern for our constituencies' safety, we have decided that this year's tree would be more responsibly available to our families in the form of a **'virtual awareness tree' on our website.**

I would encourage you to inform your extended family members, friends, support groups and childhood cancer families at your child's hospital about this holiday's 'Childhood Cancer Awareness "e-Tree!"

Please participate in this event as we continue to build awareness that childhood cancer does not 'rest' during these days of increased focus on terrorism in our country.

Palliative or Hospice Care: *Does my child need this service?*

By Joanne Hilden MD and Sarah Friebert MD

When your child is diagnosed with cancer, you enter a world of clinical trials and cancer therapies, of procedures and tests and uncertainties. This world has a new language, and unpredictable roads that are not always well lit or labeled. You enter scared but hopeful, and you need to be able to trust your guides.

Obviously your hope, and your child's doctors' and nurses' hope, is that your child will be cured. Indeed, the world of pediatric oncology is one of very successful treatment, largely accomplished through clinical trials. The Children's Oncology Group (COG) is rightfully proud of its track record of therapeutic protocols that have dramatically increased the rate of cure of childhood cancer in the last 40 years.[1] Still, a significant number (about 30%) of children with cancer do die of their disease. At the same time that we continue to focus on curing cancer, we must pay more attention to the special needs of these children and their families.

We founded the COG End-of-Life Care Subcommittee for this purpose. We did so at a time when both the public and the health care community were awakening to the need to improve the medical and psychosocial care of people with life-threatening conditions. People are saying that their needs are not being met, that their pain is not being adequately controlled, and that they are not prepared enough, as they or their loved ones go through the process of dying. The medical community is now responding to that call for action by trying to determine what exactly the problems are, and how to solve them.

So you may have started to see articles about "palliative care" and hospice care, or you may have had your child's health care providers bring it up. In this article, we would like to give you background information, and then provide information as to how you might think about how this applies to your situation, or that of someone you love.

It is important to define these terms up front. **<u>Palliative Care</u>**, as defined by the World Health Organization (WHO), is care that addresses the physical, emotional, psychological, and spiritual needs of the dying in a compassionate and all-inclusive fashion.[2] Quite simply, it involves comprehensive and family-centered care that is designed to prevent and relieve suffering (National Cancer Policy

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Cognitive Late Effects To The Brain, Part II

By Nancy Keene and Kevin Oeffinger MD

Childhood cancer and its treatment can leave survivors with unique educational needs. As discussed in the previous article (Candlelighters Quarterly, Summer 2001), treatments that sometimes affect school performance are brain radiation, intrathecal methotrexate, high-dose systemic methotrexate, and brain surgery. In addition to these treatments, learning potential can be impacted by tumor growth, numerous or lengthy hospitalizations, persistent fatigue, hearing or vision loss, fine or gross motor impairments, and social difficulties.

The survivors most at risk for brain damage are children and teens treated for leukemia, brain tumors, and tumors of the head and neck such as rhabdomyosarcoma. Very young children (less than five and particularly less than two) whose brains are growing and developing are more at risk than are older children or teens. Changes in the way children or teens think, remember, and learn are called cognitive late effects.

Types of late effects

Learning difficulties usually become evident two to five years after radiation to the brain. They can arise immediately after surgery or after very high-dose radiation to the brain. Typically, problems are noted in mathematics, spatial relationships, memory, problem solving, attention span, and concentration skills. These late effects can cause changes in learning style as well as social behavior. It is important that parents and educators remain vigilant for potential learning problems to allow for quick intervention.

One very common late effect is slow processing speed. Children with this late effect respond more slowly than do their peers. They take longer to digest information and respond appropriately. Slow processing speeds can affect learning and may impact the ability to make good judgments. The amount of information the survivor has available to make decisions is lessened because the process of considering options is slow. Again, this is not a universal late effect, but can affect a percentage of survivors.

> ***The survivors most at risk for brain damage are children and teens treated for leukemia, brain tumors, and tumors of the head and neck.***

Higher doses of radiation cause slower brain processing speeds and greater drops in IQ scores. The location of the tumor also influences the type and severity of learning disabilities that may develop. For example, children with temporal lobe tumors may have problems with memory. Learning may also be affected by medications used to treat seizures, surgical complications, hydrocephalus, vision problems, and hearing problems.

Parents of children who had cranial radiation, even at doses as low as 1800 cGy, sometimes report that the child's affect (emotions shown on the face) changed. Rather than a face that reflects what he is thinking and feeling, his face appears expressionless. This can impact making and keeping friends, as facial expressions and other body language are a big part of effective communication. Other parents notice reduced curiosity and interest.

Surgery to the brain can cause a host of late effects. The body system and amount of damage depend on the part of the brain that was operated on, the amount of healthy tissue that needs to be removed, and complications after surgery. These late effects can affect survivors' education, social life, relationships, and job performance. The effect on individual children is quite variable. Some children have no late effects, some develop very subtle disabilities, while others develop life-altering problems.

Identifying late effects

Signs of possible learning disabilities are problems with:

1 Handwriting
2. Spelling
3. Reading or reading comprehension
4. Understanding math concepts, remembering math facts, comprehending math symbols, sequencing, and working with columns and graphs
5. Remembering and copying shapes
6. Learning to ride a bike or tie shoes
7. Auditory or visual language processing (trouble with vocabulary, blending sounds, and syntax)
8. Attention deficits (some children become either inattentive or hyperactive or both)
9. Short-term memory (trouble following multi-part instructions)

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Cognitive late effects to the brain *continued...*

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10. Information retrieval
11. Social maturity and social skills
12. Recognizing faces and understanding facial expressions or gestures
13. Understanding deceit, cunning, or manipulation
14. Planning and organizational skills.

The first test is called a baseline. The baseline is used as a yardstick to measure future changes in brain functioning.

Addressing these issues with schools can be tough because these disabilities are very different from those the schools are most familiar with. It usually takes a lot of time and effort to get the best and most appropriate education for the survivor with cognitive problems. The first step is to identify whether or not your child has any cognitive late effects of treatment. Any child at risk for cognitive problems should have neuropsychological testing done as soon possible after diagnosis. This can happen after treatment starts, when the child starts feeling better, or can be done after treatment ends. The first test is called a baseline. The baseline is used as a yardstick to measure future changes in brain functioning.

PhD psychologists who specialize in evaluating how children learn and think administer neuropsychological tests. These tests usually take four to six hours, and are done over two days for younger or very fatigued children. All of that time is spent with the child, and the parent(s) are interviewed separately. The psychologist gives a series of general tests appropriate for age level, then another series of more and more specific subtests based on the results of the general ones. Pediatric psychologists usually make the testing fun for children.

Some parents have this testing done through the schools, while others have it done by experts at the treating institution. Neuropsychological tests are very different from tests that measure educational level.

Your legal rights

The Individuals with Disabilities Act requires that every public school must provide free and appropriate education in the least restrictive environment to all handicapped individuals between the ages of 3 and 21 years. That means providing, free of charge, special education programs, speech therapy, occupational therapy, physical therapy, psychiatric services, augmentative communication techniques and technology, and other interventions as needed to help the child learn. These laws have been extended by the Individuals with Disabilities in Education Act (IDEA). The major provisions of these laws are the following:

All children, regardless of disability, are entitled to a free and appropriate public education and necessary related services. Schools are required to provide an individually designed instructional program for every eligible child, including early intervention programs for at-risk infants and toddlers.

Children will receive fair testing to determine if they need special education services.

Parents of children with disabilities participate in the planning and decision making for their child's special education.

Children with disabilities will be educated in the least restrictive environment, usually with children who are not disabled.

Parents can challenge the decisions of the school system, with disputes being resolved by an impartial third party.

These laws cover survivors of cancer whose medical problems affect their educational performance, under the categories known as "other health impaired" (OHI), "traumatically brain injured," or "learning disabled." Special education services are also available if the child's medical condition limits energy, alertness, or strength. Many survivors do not need special help in school, but those who do have a legal right to it. See http://www.ed.gov/offices/OSERS/IDEA/ for the full text of IDEA and related information and updates.

Children on and off treatment may also be eligible for services and accommodations under Section 504 of the federal Rehabilitation Act. This law applies when the child does not meet the eligibility requirements for specially designed instruction, but still needs accommodations to perform successfully in school. For example, special accommodations to address health needs can include a water bottle on the desk, reduced homework during periods of illness, waiving regular attendance/tardy policies and procedures, or additional time to get to class. A child off therapy with cognitive impairments that do not meet the IDEA requirements might need to have accommodations that eliminate timed tests or provide more time to finish written assignments.

Of course, each school district has different interpretations of the requirements of the law, and implementation varies, so you should contact the school superintendent, director of special education, or special education advisory committee to obtain a copy of the school system's procedures and regulations for special education. Depending on the district, this document may range from two to several hundred pages.

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Palliative or Hospice Care?…....*continued...*

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Board). Health care systems are now more appropriately applying that definition to the care of people who are seriously ill, not just the dying. In other words, we have begun to recognize that anyone facing a life-threatening illness deserves to have their symptoms managed (especially pain) and their non-physical needs met. Whatever the outcome, people are much more able to face illness with dignity and energy if they receive compassionate, holistic care that addresses all of these areas.

Hospice care, on the other hand, is care that is indeed focused on patients with a terminal prognosis. What has been confusing is the fact that there are some free-standing hospices, so some have come to define a hospice as a "place." It is, rather, a system or philosophy of care that focuses on patients who are going to die. Hospice care encompasses the same principles as palliative care, but focuses more on promoting quality of life, fostering choice in end-of-life care decision-making, and supporting effective grieving for patients and their families. Traditionally, Medicare coverage for hospice care has been limited to those with a 6-month prognosis, which is very hard to determine accurately. It is especially hard to predict in children, since they tend to have healthier organ systems than adults and they tend to "live until they die" rather than quietly dwindle away.

At this point, you may be wondering: if there are services available aimed at providing comprehensive and compassionate care for people who are dying of their disease, why aren't these services utilized more; and why are children still suffering as they die?

Well, that question has been looked at from a number of perspectives. In 1997, the Institute of Medicine published a comprehensive review entitled, *"Approaching Death: Improving Care at the End of Life."* The barriers identified to excellent end-of-life care were many:

1) Financial: there is poor coverage for hospice care, often tied to the 6-month prognosis rule;
2) Education deficiencies: health care providers are not traditionally taught how to care for dying patients;
3) Health care system fragmentation: care is often delivered in different systems by many providers, often with poor communication between them; and
4) Patient and family issues: many patients see hospice care as "giving up" so they don't want to use it.

There are many more problems than these, especially when it comes to

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Cognitive late effects to the brain continued…

Also write to your state Superintendent of Public Instruction to obtain a copy of the state rules governing special education.

Armed with this information, you will be prepared to be an advocate for your child as she goes through the several steps necessary to determine the best possible education available to her. The steps that will be taken are referral, evaluation, eligibility, developing an **individual education plan (IEP)**, and annual review.

The IEP

Parents or teachers can make a referral by writing the school principal to request special education testing. Some school districts automatically set up an IEP for any child who has had cranial radiation, while other school districts are extremely reluctant to even evaluate struggling children for possible learning disabilities. Therefore, it is best for the parent or physician to send a written request to the principal, stating that the child is "health impaired" due to treatment for cancer, list his problems, and request assessments and an IEP meeting.

Once the referral is made, an evaluation is necessary to find out if the school district agrees that the child needs additional help, and if so, what types of help would be most beneficial.

Children with a history of chemotherapy and/or radiation to the brain usually require thorough neuropsychological testing, which is best administered by psychologists experienced in testing pediatric patients. Most large children's hospitals have such personnel, but it sometimes takes very assertive parents to get the school system to use these experts. Your written consent is required prior to your child's evaluation, and you have the right to obtain an independent evaluation if you believe that the school's evaluation is biased or flawed in any way. However, you are responsible for this cost unless the district agrees or you follow the appeal procedures.

After the evaluation, a conference is usually held to discuss the results and reach conclusions about what actions will be necessary in the future. Make sure that in all written correspondence with the school, you clearly express a wish to be present at all meetings and discussions concerning your child's special education needs. You and your spouse know him best, and you have the right to be there.

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Palliative or Hospice Care? ...*continued...*

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providing this care for children. Subsequent reviews by others, including the National Cancer Policy Board, have identified the same issues.[3] In particular, most of the services available have, until recently, focused on adults, so most palliative or end-of-life care providers are much less experienced in caring for children.

In pediatric oncology specifically, we have looked at these issues from the perspective of parents of children, and of the doctors. Dr. Joanne Wolfe, at Boston Children's Hospital, undertook a comprehensive survey of parents of children who died of cancer. The findings, reported in the New England Journal of Medicine, were striking.[4] Dr. Wolfe found that 80% of children suffered pain, nausea, and/or other symptoms in the last month of life, and that these symptoms were not successfully treated most of the time. These symptoms were recognized by the parents more often than by the physician.

At the same time, the American Society of Clinical Oncology (ASCO) surveyed its membership on end-of-life care practice. Dr. Hilden summarized the pediatric oncologists' responses in the Journal of Clinical Oncology.[5] The great majority of pediatric oncologists (>90%) report that they are competent or very competent in managing pain and other symptoms at the end of a child's life. Yet Dr. Wolfe's data would suggest that symptom control at the end of life remains a significant problem.

Where does this all fit into the care of a child with cancer? Let's take the individual components of palliative care separately (physical, emotional, psychological, and spiritual care) and think about how and when they apply.

First, palliative care addresses the physical needs of an ill child. This means that symptoms are controlled: pain, nausea, vomiting, diarrhea, itching, etc. Those of us in the field want very much to stress that there does not have to be uncontrolled pain in a child's last days and weeks. But here is where that problem with provider education comes in—most doctors and nurses have not been taught how to control symptoms in people at the end of life. So if your child's team is having problems managing symptoms, you may need to call in a palliative care team or a pain team. If there is not one available, there are on-line resources they can use, or the team can access the WHO pain guidelines.[6]

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Second, palliative care addresses the emotional and psychological needs of the ill child and family. This is the heart of the matter, isn't it? Because in this category, there is the issue of fear. It is a paralyzing fear to think that your child might die. Most of us parents cannot think about that possibility for too long without forcing it out of our minds. But as the parent of a child with cancer, you had to think about it at the time of diagnosis, or certainly at the time of relapse if that happened.

Think for a moment about how this fear affected your ability to process information from doctors, and to make medical decisions for your child. You'll probably remember a time of feeling helpless and powerless. Most likely, getting good medical information, and understanding it, was part of the process of getting past that. How much more true this is if you are now receiving information that your child will probably die. The need for good, complete, understandable information about what will most likely happen as a child dies is extremely important, but the fear of talking about it is a huge obstacle to that, both for doctors and for parents. A palliative care or hospice team can be of great assistance with this process, especially as things begin to change on a daily or even hourly basis. These professionals help both with overcoming these fears as well as with having the difficult conversations.

There are so many more emotional and psychological issues other than fear. Some of these are how to deal with talking to your ill child and your other children about illness and death, how to deal with anger, and how to help you and your family through grief and bereavement. While these issues are all beyond the scope of this article, suffice it to say that the palliative care and hospice professionals can help with these issues. It is especially important to know that if your child dies, this help and support will extend well beyond your child's death, usually for at least a year or as long as your family needs assistance. At the end of the article there are some references and resources for you.

Last, palliative care helps with spiritual issues. While this area is complex and so different among families, there are certain to be some questions regarding the meaning of the experience for your child and family. Every hospice team has a chaplain or spiritual counselor, and palliative care teams (and perhaps also your oncology team) have such resources as well. While your initial reaction may be that you don't need this (you're not "religious" or you have your own pastor or other resources), don't underestimate the value of a conversation with the palliative care or hospice team

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Cognitive late effects to the brain continued…

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The Individual Education Plan describes the special education program and any other related services specifically designed to meet the individual needs of your child with learning differences. It is developed by parents and professional educators to determine what the student will be taught, and how and when the school will teach it.

It is in your child's best interests to make the IEP as specific as possible. Following are some examples of things that parents have included in their child's IEP:

1. School provides a keyboard for children who have difficulties writing.
2. A second set of books to keep at home for children who tire easily carrying books or for those with attention difficulties who forget to bring books home.
3. A day planner with all homework assignment reviewed at the end of each day.
4. One-on-one help in the resource room to help organize large assignments into manageable chunks.
5. A locker close to the homeroom for teens with visual spatial difficulties (get lost, don't know left from right, etc).
6. Social skills training for children with social difficulties.

It is best to create a positive relationship with the school so that you are able to work together to promote your child's well-being. If, for whatever reason, communication deteriorates and you feel that your child's IEP is inadequate or not being followed, there are several facts that you need to know:

1. Changes to the IEP cannot be made without parental consent.
2. If parents disagree about the content of the IEP, they can withdraw consent and request (in writing) a meeting to draft a new IEP.
3. Parents can request to have the disagreement settled by an independent hearing officer.

Early Intervention services for preschoolers

Federal law also mandates early intervention services for disabled infants and toddlers, and in some cases, children at risk of having developmental delays. Infants, toddlers, or preschoolers with cancer may be eligible for these services in order to avoid developmental delays caused by cancer treatments. These services are administered either by the school system or the state health department. You can find out which agency to contact by asking the hospital social worker or by calling the special education director for your school district. The law requires services not only for the infants or preschoolers, but for the family as well. Therefore, instead of an IEP, an **Individualized Family Service Plan (IFSP)** is developed.

Services for middle and high-schoolers

Transition planning should begin in the early years of middle school, when the student's peers are beginning to gain work skills and amass credits toward high school graduation. For some survivors, extra support will be needed to make the transition from high school to adulthood go smoothly. The written transition plan is called an **Individual Transition Plan (ITP).** Students planning to attend trade school, a two-year community college program, or a four-year college program need information far in advance on which high school courses will be required for entry. This is especially important for those students with disabilities who carry a lighter course load, as they may need to make up some credits in summer school or via correspondence courses. Transition programs should address the move from high school to trade school, community college, or a four-year college program. Students are eligible for publicly funded education and/or services until age 22 if needed. Tuition in some programs may be covered for some students, in full or in part. Special education services and help for students with learning disabilities are available on campus and in the dorms at many colleges.

Sources of support

There are many ways to find the help you need to address your child's cognitive changes. Following are some good starting points for getting the information and support you need.

Books

1. *Childhood Cancer Survivors* has chapters on brain late effects, navigating the system, and an extensive bibliography of books to read on this topic. You can get the book from your local or medical center library or order online (e.g. amazon.com or from the publisher 1-800-998-9938.
2. *The Source for Non-Verbal Learning Disabilities* by Thompson (LinguiSystems, 1997, 1-800-PRO-IDEA)

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Hip Hats Are FREE To A Cancer Child In Need

Hip Hats are cool hats with human hair. They're soft, comfortable, and fun to wear. They are provided free of charge to children under the age of 21 with any type of cancer.

Orders can be shipped directly to the child.

Call Christine Heinen for a catalog.

Toll-free:1-877-447-4287.
Outside of the U.S. please call 813-229-2377.

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outlines specific disabilities and detailed ways to address each.

3. *Negotiating the Special Education Maze* by Anderson and Chitwood (Woodbine House 1997) walks you through the IEP and ITP process.
4. *Colleges with Programs for Students with Learning Disabilities*, Sixth Edition by Mangrum and Strichart (Peterson's Guides 2000)

Websites
www.acor.org/ped-onc click on "family issues" then "back to school" for lots of helpful information from parents of kids with cancer.
www.ldonline.org--a comprehensive, interactive guide to learning disabilities for parents, students, and teachers.

Hospital educational liaison
Some clinics with comprehensive late effects clinics have an educational liaison. These professionals will help you get neuropsychological testing for your child and will also work with you to get appropriate educational services. Some liaisons communicate directly with the schools to help them understand and interpret the testing results. Sometimes, the liaison will accompany the family to IEP meetings as an advocate.

Other parents
Many families find support in discussing issues and sharing experiences and suggestions in support groups. Check to see if your treating institution has support groups for families of long-term survivors. If not, or if you don't like face-to-face groups, you might consider joining an online support group. You can join a group that is just for parents of survivors at: http://www.acor.org/ped-onc/cfissues/maillist.html Also, most school districts have parent groups for families of children with learning disabilities. By joining one of these groups, you will get a lot of information from those with more experience, as well as tremendous emotional support.

Hired advocates
Many communities have professional advocates whom you can hire to study your child's particular situation and make suggestions for the most appropriate program. These advocates are often retired special education teachers or psychologists who specialize in educational issues. Often, they will accompany the family to IEP meetings.

School personnel
School personnel, both in the individual schools and at the district level, can be very helpful in your quest for a strong and appropriate program for your child. Try to find one person in the system and forge a strong relationship. Adopt the attitude that you and the school are on the same team to help craft a plan for your child. Show appreciation when things work well. Making deposits into a "good will bank" will help if you need to advocate strongly when services fall through the cracks.

Children with special educational needs need strong advocates in their families and schools. The benefits are well worth the effort.

Candlelighters would like to once again thank Dr. Kevin Oeffinger and Nancy Keene for their invaluable contributions.

Dr. Kevin Oeffinger MD *directs a multi disciplinary program for young adult survivors of childhood cancer at UT Southwestern at Dallas TX and is partially supported as a Robert Wood Johnson Foundation Generalist Physician Faculty Scholar. He enjoys backpacking, running and hiking with his wife Patty, 16-year-old son Daniel and 13-year-old daughter Ashley.*

Nancy Keene *is the author of Childhood Leukemia, Childhood Cancer (with co-author Honna Janes-Hodder), Your Child in the Hospital, Working with Your Doctor and Childhood Cancer Survivors (co-authored with Wendy Hobbie RN and Kathy Ruccione). She is former Chair of the Patient Advocacy Committee of COG (Children's Oncology Group) and mother of 13-year-old Kathyrn who is a survivor of high risk ALL and 11-year-old daughter Alison.*

Palliative and Hospice Care?...*continued..*

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chaplain. They are more experienced with dealing with people who are going through the type of crisis that you are experiencing.

The American Academy of Pediatrics (AAP) has issued a position statement about the care of children at the end of life.[7] This paper outlines recommendations for personnel who are essential to provide excellent end-of-life care for children. The list includes, along with doctors and nurses, the staff we have mentioned: social workers, child life workers, child psychologists, and spiritual counselors. Palliative care and hospice teams have these staff, and you're probably realizing that most pediatric oncology teams do as well. So why are there still these problems?

The reason is that we don't yet know how to best put these pieces in place for children who may die, and their parents and siblings. The COG End-of-Life Care subcommittee exists to try to answer that question through research and education Here are some examples:

When a child is so ill that he or she may die, parents need information to help them prepare, and to help them make decisions that won't be regretted later. Many in the field have taken the position that this information should be provided, and maybe even a palliative care consultation made, at the time of diagnosis. But is this really the best time? Only research, with parents and children as our partners, will answer that. And only a systematic review of the educational materials and processes that are out there will allow us to improve education for nurses, doctors, and families so that people are better at talking about these crucial issues and making informed decisions when the time comes. Our COG subcommittee has an education subgroup that has been formed for just this purpose.

Another example is that of a child with significant pain who is on medication that is only partially relieving the pain. How do we measure the pain that child is feeling so that we know if our interventions are working? What is the best medicine to add, and at what dose? Is that child having other symptoms, or side effects from the pain medicines, that we need to better manage? Children are not just small adults; their bodies process drugs differently. This is another area of research that the COG group is beginning to explore.

In a nutshell, that is what COG is doing. We want to partner with you, the parents of our patients, to make this situation better. What can you do?

First, you can inform yourself. Have a look at some of the references and resources at the end of the article. Find out about what resources are available in your community for palliative and hospice care. Talk to some of those professionals, and learn from them how valuable their services can be <u>even to those children who will survive their cancer</u>. When you think about it, it makes so much sense to apply these standards of excellent symptom control and emotional support to all children with cancer.

Second, you can talk to your doctors and nurses in more detail about how to take care of your child's pain, whatever the circumstances. You can learn that the fact that some pain requires strong medicine does <u>not</u> necessarily mean that your child is dying soon. You can also learn that children with cancer pain do <u>not</u> become addicted to strong pain medicines; in fact, addiction in children is extremely rare, and when it does happen, it is mostly as a result of under-treated pain. And you can make a plan with your child's team for who will take care of your child's pain, be it 2:00 in the afternoon, or 2:00 in the morning.

Next, you can think more about the benefit of doing research in this area. All of those involved in dealing with childhood cancer, whether they are patients, doctors, parents, or nurses, have benefited from the excellent research done in how to treat childhood cancer. We should all be more open to doing research into how best to relieve suffering for those children who die.

Once you have educated and informed yourself, you can help by spreading the word to other families who may benefit from hospice and palliative care services. Often when frightening information comes from other parents, families are more able to be open to new ideas and to accept help. Whether you're involved in a local support group, an on-line network, or an informal gathering of parents in the hospital hallway, you can help to dispel some of the myths that people believe about hospice and palliative care. Specifically, you can help by assuring parents that their child's health care team is not giving up on them if they mention hospice or palliative care – they only want to provide the best, most inclusive, most compassionate care available for children

We are all in this together. We want the best for your children. We want your children to survive, and we continue to have that as our goal, first and foremost. But if that is not going to happen, our goal becomes this: to help your children to have the best "life before death" that they can, and to help you feel as empowered and hopeful as possible throughout the process.

References: See bottom of page 10...

Candlelighters would like to thank Dr. Joanne Hilden and Dr. Sarah Friebert for their on-going work on behalf of "our children."

An Unlikely Angel

By Nancy Lowell George

The occasion was worthy of a celebration. After two and a half years of chemotherapy, my son was about to take what we hoped was his last taste of "yucky medicine," his last treatment via a spinal tap, the last search for a vein to start another IV.

I know of other parents of children with cancer who hosted slumber parties to celebrate the end of chemotherapy. One mom bought her daughter a decorated cake. Some didn't celebrate for fear of a relapse and this not being the end of chemotherapy at all.

But none of these ideas seemed right for Andy. He was diagnosed with leukemia at age four, and started kindergarten near the end of the worst part of his treatment. Many of his friends didn't know he had cancer and would be baffled by the reason for the party. He played soccer with the neighborhood team and took swimming lessons at the local pool. His Indian Guide name, "Soaring Eagle," offered a hint of his once semi-bald state, but for the most part, the weakness, nausea, and pain of chemotherapy were behind him. As the youngest of three children, he had long admired his siblings' trophy collections and eagerly awaited accumulating a collection of his own. The highlight of his meager collection was a wobbly karate trophy he bought at a garage sale.

For his determination, courage, and spunk, he had certainly earned a trophy. In addition, trophies would make small but tangible thank you's to the medical team who had invested so much compassion in his care.

The trophy shops with large ads in the Yellow Pages could make the trophies, but could not meet my deadline; these trophies had to be ready in five days, in time for the last treatment.

The only shop that could meet my last minute schedule was a one-man shop located in the back corner of a warehouse in a rundown business district. As I browsed the dusty showroom, the owner ignored me, exchanging jokes with a friend over the telephone. Finally he offered his help. "What kind of event do you need a trophy for? Football? Baseball?"

I explained this was an occasion he may not have encountered in the trophy business. He suggested a muscular man holding the earth, but it wasn't what I had in mind.

After rattling about in the back room, he emerged with a winged figure, "The Goddess of Victory," he said. She looked more like an angel to me, which seemed appropriate. Now that our family has been touched by childhood cancer, I am convinced of the presence of both earthly and heavenly angels.

We selected the tallest trophy for Andy and inscribed on it, "Champion." His doctor, nurse, and the cancer clinic staff were declared "The Best in the World." The phlebotomist, Esther, who weekly drew his blood, was "The Most Patient Person in the World."

The trophies were ready the night before the last treatment. We carefully wrapped each one, leaving one trophy. Who had I forgotten? Andy brought the trophy to me." This is a gift for you from the trophy shop owner," he explained. The inscription below the winged figure read, "Mother-of-the-Year."

To my surprise, an earthly angel, disguised as a cranky trophy-maker, had remembered me.

References for Palliative and Hospice Care? (continued from page 9)

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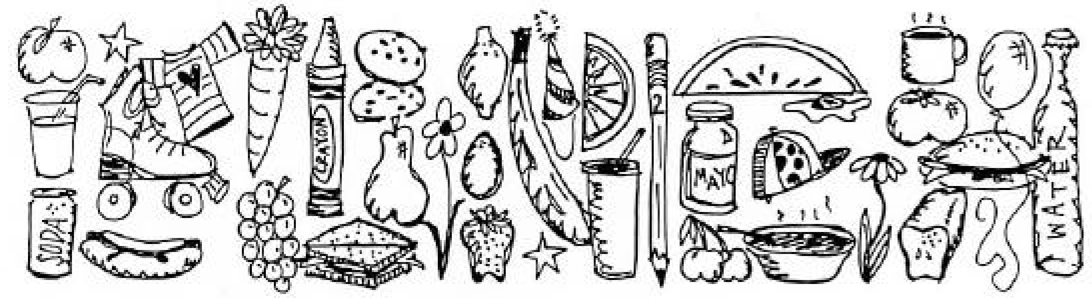

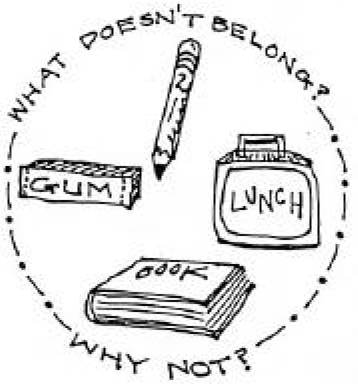

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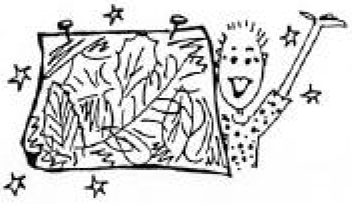
LEAF PICTURES...

Here is a fun craft you can make in the Fall with leaves you find!

#1- Place leaves on a flat surface... (you may want to ask an adult for a good spot for your project!) Place a sheet of clean paper on top of the leaves.

#2- Hold your paper so leaves don't slip... using older colored crayons, fill your paper with fall colors. Press hard.

#3- Watch as the colors begin to show your leaf patterns below! Try different kinds of leaves-
Have fun!!



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CONTACT INFORMATION

The Candlelighters Childhood Cancer Foundation™
P.O. Box 498
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Ph: 301-962-3520 1-800-366-2223
Fax: 301-962-3521
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Ruth Hoffman
Executive Director & Newsletter Editor

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Link to Candlelighters Childhood Cancer Foundation Website at: http://www.candlelighters.org to find the latest copy of our quarterly newsletter, our mission statement, publications list, local group information and membership sign up form.

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We encourage you to continue to visit the site regularly as new links to affiliated organizations and other health-related websites are added regularly.

> ***Alone we can do so little.***
> ***Together,***
> ***we can do so much!***
>
> ***Helen Keller***