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Part I: Modern Medical Therapy

\*\*\*\*\*Advances in care for children bring 50 percent chance for what was once fatal disease.

DALLAS--Dr. George Buchanan, head of the oncology team at Children's Medical Center in Dallas, believes that the 'he died, anyway' syndrome may play a large part in the problem of parents refusing traditional chemotherapy and other treatments for children with cancer

Cancer therapy has had particularly "bad press" says the pediatrician, who, besides his duties at CMC, is an associate professor at The University of Texas Health Science Center here. That's because nearly everyone in the past had a family member or friend go through often futile, as well as uncomfortable, or even painful, treatment accompanied by impleasant side effects. Then they say, 'He died, anyway."

Besides pain caused by the disease process, as well as some of the tests and treatments, it is true that there may be side effects from conventional therapy. These include hair loss, extreme episodes of nausea and vomiting, internal hemorrhaging and infections caused by the suppression of the body's immune system by drugs and radiation.

"The feeling is often that the treatment is worse than the disease." While there might have been some truth to this statement, especially in the case of children in the past, it is not true today. Up to 15 years ago--or even 10--there was not much hope for the child with cancer. Today most cases, including both those with tumors and leukemia which used to be fatal, are treatable and curable about 50 percent of the time, Buchanan says.

At least three sets of parents in roughly the last year have removed their children from treatment at the Dallas health science center and its major teaching hospitals. Two of these children were being given chemotherapy by Buchanan's team, while a third, an older adolescent, was receiving radiation as a patient in the Department of Surgery. All of the three have since died.

One four-year-old was discovered to have malignant lymphoma, or cancer of the lymph system. He was removed from treatment both in Dallas and at another major medical center, which was cooperating with the case. The mother checked her son out against doctor's orders to take him to a chiropractor who practices nutritional "cures."

A girl not yet three, died in another state where she had been taken despite a court order requiring treatment for acute lymphoblastic leukemia, the most common childhood leukemia. She was kept from treatment because the parents thought "God would heal her," the physician said. And at other times the family refused to believe she had the disease at all. Buchanan thinks the 'died, anyway' syndrome also played a role in this case. But whatever the reason, the father was jailed for contempt of court although he claimed he did not know where the child and her mother were.

The third, a 16-year-old, was being treated for a brain tumor. Eventually given adult status by the court, he and his family had sought help from a doctor who prescribed laetrile treatments, thus avoiding the effects of radiation therapy he had been experiencing.

The irony of the 'he died, anyway' syndrome, Buchanan says, is that children like these, who receive the latest treatments at modern medical centers have a better chance than ever before in conquering their diseases. And while side effects from such cancer treatments as chemotherapy and radiation may range from unpleasant to quite awful for some patients, these states are temporary, and most are reversible.

There are about 10 different kinds of cancer in children with about a 50-50 split between leukemia and tumor-type cancers. About 80 percent of the leukemia patients have acute lymphoblastic leukemia (ALL). The remaining 20 percent have acute myeloblastic leukemia (AML), a grouping of cancers more often seen in adults. With the latest in treatment protocols, says the pediatric oncologist, the average long-term survival and possible cure rate (defined by Buchanan as remission up to five years) is now about 50 percent. Great progress has been made in treatment for AML, also, but the success rates lag far behind that for ALL.

Because it has its own special name--leukemia--many people do not realize that this disease is a form of cancer. Others know it as "cancer of the blood." This term is descriptive of the disease, which involves the distorted growth and proliferation of leukocytes (white blood cells or corpuscles that attack invaders) or similar defense mechanism in the blood or blood-forming organs.

Tumors of the brain are the most common type of solid tumors. Lymphomas (abnormal growth of lymphoid tissue), a classification which includes Hodgkin's disease, are seen often at Children's. Other solid tumors include Wilms', a tumor of the kidneys, and neuroblastoma, a tumor of the nervous system, which occurs in the back of the chest or abdomen.

The oncology team meets several times a week to consider current cases. Buchanan says that a multi-disciplinary approach with chemotherapy, surgery and radiation is used with patients with solid tumors, each patient receiving an individual approach to his or her therapy. Leukemia patients are treated mainly with drugs, or chemotherapy, also in individual protocols, according to the type of disease, its progress and the child's response to treatment.

The philosophy of the medical team is to try to treat the child as an out-patient whenever possible. Unless surgery is involved, the initial hospital stay usually lasts from one to two weeks. Then the patient usually comes back for testing and medications once a week for two to two-and-a-half years. If the child does well on his or her treatment plan and is lucky, another hospitalization may not be required. Re-hospitalization, however, is a common occurrence among patients because the drugs and radiation suppress the child's immunity system, often allowing other infections to take over.

Not only is Children's a major referral center for Texas cancer patients, the hospital and its medical staff are involved in work that is attracting national attention. Many of the tumor and leukemia patients are participating in studies funded by the National Cancer Institute. These programs are aimed at finding the most effective treatments for these diseases through the Pediatric Oncology Group, an association of 35 top cancer treatment institutions around the country.

The Dallas oncology team is also involved with a study of 120 patients, 50 in Dallas and 70 in the well-known Milwaukee Children's Hospital. Also, Buchanan and his associates are part of a big National Insitutues of Health study on the treatment of Wilms' tumor, involving major pediatric oncology teams across the country. These working relationships enable CMC patients, like Brett Brown (not his real name), who lives in a Dallas suburb, to receive the most up-to-date treatment available.

Brett was just two years old when he was diagnosed with leukemia at Children's. He was a very sick little boy, who suddenly refused to walk because of the pain in his legs and whose nose suddenly wouldn't stop bleeding. When his regular pediatrician undressed him for an examination, he turned to Brett's mother:

"How long has he had these bruises?" he asked.

Leslie Brown was shocked. On her baby's back were three large splotches, dark and ugly.

"They weren't there when we left home," she answered, her voice shaking.

These symptoms, along with an elevated white-cell count, caused the doctor to send Mrs. Brown and Brett to Children's immediately for a bone-marrow test.

"It was frightening," says husband Mike. "I think Leslie had an idea what might be wrong--but I didn't want to believe it might be leukemia.

'We both thought the disease was always fatal. But when we talked to the doctors they explained his prognosis in great detail. And they've always been willing to answer any questions we have. The doctors came to see Brett several times a day and always had time to talk."

Now off treatment for two years and doing fine, Brett still goes in for regular medical checks. Buchanan says he is a model patient, who responded well to treatment. His parents say he's a normal boy leading a normal life playing soccer and neighborhood football.

Brett himself rarely refers to his two-year ordeal when he was receiving chemotherapy and radiation treatments. However, every year at Christmas he dons the long-tailed Santa Claus cap that he wore when medication caused him to lose his hair.

"This is the Santa hat I wore when I was bald," he always says.

Don Hooten, also six years old, is an "outdoors boy," as his mother calls him. The second-grader manages to keep up his studies even with his frequent trips to Dallas for his leukemia treatment. Don, who does not tolerate the medicines well and takes smaller doses, is hospitalized every eight weeks for four-day periods. In addition, he has to visit the oncology out-patient clinic once a week.

The Hootens, who live on an East Texas farm, are very supportive of the kind of care Don is receiving at Children's.

"Nobody wants to take treatment like this," says Bobby Hooten, Don's father. "But if you get into the situation, you give it all you've got. If I didn't see that Bobby gets the best treatment possible and something happened, I'd feel I didn't do all I could."

Certainly that's the way the oncology staff at Children's feels about it, as do many families of former patients with childhood cancers.

"Some of the children who received these early improved treatments for cancer are now in their late teens and early 20s," says Buchanan. "If you have any doubts about whether or not it's worth it, go ask them."

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