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FORTY YEARS' WAR

A Place Where Cancer Is the Norm

By [GINA KOLATA](#)

HOUSTON — M. D. Anderson [Cancer](#) Center has a mission statement, and everyone who works there, from the president to the cleaning crews, can state it like a catechism: to “eliminate cancer in Texas, the nation and the world.”

For the nearly 90,000 patients who will go to the [center](#) in Houston this year, that mission cannot be fulfilled soon enough. They and their families arrive at the world’s largest freestanding cancer hospital from around the world, often leaving behind jobs and stashing children with relatives for months. Some rent apartments or stay in mobile home parks near the hospital.

They enter through a soaring lobby, with cheery aquariums and exuberant volunteer greeters eager to help in any way. They come looking for hope.

But there is no mistaking what this place is: the front line of the frustrating war on a still largely incurable disease.

Doctors are encouraged to try everything, and when insurers balk, they pick up the phone, repeatedly, hoping to persuade them to pay for what may be unconventional treatments.

The federal government gives more cancer research money to this hospital than to any other, and the hospital has an abundance of specialists in many forms of cancer, including rare ones. [Medicare](#) offers more generous reimbursement, and the hospital offers treatments that often go far beyond what can be offered at most other places.

“I tell young physicians who are starting out here that the big limitation is imagination,” said Dr. Martin Raber, an oncologist — and a cancer patient himself — at Anderson. “If you are good at what you do and you have great ideas, we will help you find the resources you need to make them happen.”

But like a modern version of the tuberculosis sanatorium in [Thomas Mann](#)’s “Magic Mountain,” Anderson is a world where the best that medicine has to offer is often far from enough. The odds are still grim, and while there are exhilarating recoveries, the exhausting, dispiriting road traveled by many patients comes into sharp relief.

They are patients like 35-year-old Mindy Lanoux of San Antonio, who has melanoma that has spread to her liver and lungs, her odds of surviving in the single digits. She has been to the hospital 16 times in nine months, spending a week there each time for treatments so debilitating she wanted to give up. But she keeps returning, smearing peppermint oil under her nose when she walks in the medical center’s door to hide the odor.

“The smell gets to me,” Ms. Lanoux said. “It smells like cleaning products and the sickness and the medicines. It takes your brave edge off.”

Then she and her father go to her room and start putting her things away. “We don’t talk,” Ms. Lanoux said.

“There is no polite conversation. It is like an army setting up to do battle.”

Planet Cancer

With more than 17,000 employees and warrens of color-coded hallways so vast that even employees get lost, M. D. Anderson is its own parallel universe, where nothing matters but cancer. Patients sit in the lobbies and compare notes.

“Everyone in the waiting room talks about ‘How did you find yours?’ ” said June Toland, 71, of Harlingen, Tex., who is being treated for sarcoma, a cancer of connective tissue.

Every patient at Anderson has cancer. Every family member sitting anxiously in the lounges or lingering at a bedside or sleeping in a Murphy bed in a patient’s room has had the life-changing experience of being touched by cancer.

“It feels sometimes like the entire world has cancer,” said Cindy Davis, a nurse in the [breast cancer](#) clinic who has breast cancer herself.

Anderson is a quiet place. No loud pagers. The walls are decorated with vivid photographs of serene scenes, like water views. The muted colors in the hallways, soft cranberry and dull green, are meant to be soothing. There is a special room, Kim’s Place, for young people only, cancer patients and their friends ages 15 to 30, giving them a place to gather. There is a library and a cybercafe. It is a place meant to give hope.

Sometimes, as happened with Frances Anderson of Shreveport, La., that hope is realized. She discovered three years ago that she had a [brain tumor](#), but it did not start in her brain. In fact, it is not clear where it started. After being told by a doctor elsewhere that she had four to seven months to live, she ended up at Dr. Raber’s clinic, one of the few that specialize in treating patients with cancer throughout their bodies but with no obvious source for the [tumors](#).

At 66, wearing pressed jeans, her short blond hair carefully styled, Ms. Anderson has [vision problems](#) from the surgery to remove the brain tumor, and she gets tired. She still has cancer, but she exercises every day and is living with her disease, returning to Anderson every six months for checkups and scans.

Others are not so fortunate. One morning last month, [Joe Maxwell](#), 52, sat in a chair next to his hospital bed, a compression bandage around his now-useless swollen left arm, a large bandage over his left shoulder. He was going home to sit on his deck in Kerrville, Tex., a four-hour drive. He had tried everything Anderson had to offer and decided that, with an estimated two weeks left, he would go home to die.

Mr. Maxwell came to Anderson in January after his doctor told him a bump on his shoulder was a rare [tumor](#), Merkel cell carcinoma, and added, “If you have a rare tumor, you need to go where tumors are not rare.”

At Anderson, doctors tried everything they could think of — surgery, round after round of [chemotherapy](#), a clinical trial of an experimental drug. Nothing worked. Finally, the doctors suggested yet another drug.

“We spent a lot of time praying about it and just discussing it,” Mr. Maxwell said. “I wanted to go home; I was tired. They gave me a short amount of time and said, ‘If you want to go home, now is the time.’ ”

But leaving late last month was bittersweet. The doctors and nurses “have become our friends and our family,” his wife, Kathleen Maxwell, said. Anderson, she added, “has been our life for nine months.”

He died 10 days later, early in the morning of Oct. 8.

Even those who finish their treatments and live cancer-free are forever changed by the experience.

Mrs. Toland learned that lesson from her son, George Toland. Twenty-four years ago, when he was 21, he was a sarcoma patient at Anderson. One day he looked at his mother and said, "My life will never be the same."

His mother tried to reassure him, telling him that he would be fine, that he would go on to a perfectly normal life.

But he demurred, saying, "You know, Mother, it's a loss of innocence."

Mrs. Toland knew he was right.

She told him: "Most people lose their innocence in little doses as they go through life. You lost yours all at once."

Battling the Odds

Donald Berry, a statistician who is head of the division of quantitative sciences at Anderson, says part of his role at the cancer center is to provide a reality check.

Yes, it is true, as doctors and nurses there repeatedly say, that treatment has improved. Anti-nausea drugs have all but eliminated the constant [vomiting](#) that once accompanied chemotherapy. New drugs are attacking genes that go awry in cancer. Most cancer patients come and go over a period of years, for checkups, scans, treatment if the cancer is still there. In between they go on with their lives.

But there is still little that can be done for most of those whose cancer has spread. And, Dr. Berry said, "that is a fact that doctors at M. D. Anderson can have a hard time facing, understandably so."

Dr. Russell Harris, an associate professor of medicine at the [University of North Carolina](#) and a member of a board that evaluates cancer therapies for the [National Institutes of Health](#), said the temptation at major cancer centers like Anderson was to try treatment after treatment.

"Everyone is totally immersed in the idea that death is the enemy," Dr. Harris said. Such a no-holds-barred stance, he added, is spurring a growing debate in the cancer community.

"There is a lot of concern within the oncology community right now, and appropriately so, that people don't completely understand what they are getting into," Dr. Harris said.

An aggressive — and expensive — course of treatment can place a huge burden on patients. Ms. Lanoux knows that all too well. She came hoping for a cure for her advanced [melanoma](#), but got her first dose of reality the day she walked into the main lobby.

She saw patients in wheelchairs, their heads sunken on their chests. She saw patients who had lost their hair, patients wearing sky-blue masks to protect them from infections. And there were the children. She had to avert her eyes. "I still can't look at the kids," Ms. Lanoux said.

"I think we were all trying to be very brave," she said. "But it was like walking into a coffin."

Ms. Lanoux, a small blond English teacher, lives in San Antonio with her husband, also a teacher, a 19-month-old daughter, an 8-year-old daughter and a 12-year-old son. The day she arrived at Anderson, Feb. 9, was the beginning of a difficult journey at the cancer center. She has been coming about every three weeks since, staying for a week at a time.

Her problems began in August 2008 on the way to a beach vacation. She started coughing. Her doctor was not

concerned, telling her he thought she had [acid reflux](#) because she had had it when she was pregnant. He gave her Nexium. She returned in November at a friend's urging, and her doctor prescribed [cough](#) drops and [steroids](#). But she kept coughing.

Finally, in January, when she still could not catch her breath, her doctor ordered a chest [X-ray](#) to see if she had [bronchitis](#). The next week, she returned to learn the result. Her husband wanted to go with her, but she told him not to bother, it was probably just bronchitis.

The doctor "came in and said, 'This is the part I hate most about being a doctor,'" Ms. Lanoux recalled. There was a spot on her lung. A [CT scan](#) also revealed spots on her liver. And a [biopsy](#) of the spots on her liver revealed what it was. Melanoma. It had spread from an initial lesion — no one could ever find where it started — and was now threatening her life.

Ms. Lanoux's doctor in San Antonio told her to go to Anderson. "She very honestly told me, 'I don't want to try treating you,'" Ms. Lanoux said.

"I think I was in denial until last month," she said. "I had a 10 percent chance to survive five years, and I was going to do it."

She has tried everything. Immunological therapy with side effects so severe it has to be administered in the intensive care unit. It did not work. Then she started biochemotherapy — a combination of three chemotherapy drugs and two immune system hormones to stimulate her body to attack her tumors. It is a controversial treatment, said her doctor, Patrick Hwu, but some patients had lasting remissions.

Not Ms. Lanoux. At least not yet. On a recent sunny fall afternoon, she lay in her hospital bed on the 10th floor, wearing striped pajamas, blinking away tears as she told her story. She had just finished her sixth biochemotherapy treatment. Once again, she said, the therapy had made her feel "barely human."

The effects hit her hard after the second treatment.

"I got home and ordered a wheelchair, a shower seat, a walker," she said. "I am 35 years old and I have a wheelchair, a shower seat, a walker." Just a few years ago she had run a marathon.

"My husband was helping me take a shower," Ms. Lanoux said. "Of course it was awful. You're cold, you can't get enough water on you. I told him I don't want to do this again. Call Dr. Hwu. I'm not going back."

But she relented. Now Dr. Hwu wants her to try an experimental drug that takes the brakes off the immune system and might allow her body to destroy her cancer.

But the drug has not been approved by the [Food and Drug Administration](#) and is not available. Dr. Hwu knows it can have serious side effects and may not help Ms. Lanoux. But some who took the drug defied the odds, living for years. Maybe Ms. Lanoux could be one of those survivors, Dr. Hwu thinks.

And how about surgery, he asked her last month. "You can live with half a lung," he said. But she probably would have to have her entire lung removed, he learned. And a surgeon would also have to take out the tumors on her liver. It may not be feasible, Dr. Hwu said, but, he added, "It's definitely something I'm thinking about."

Dr. Hwu struggles with the grim statistics — 8 percent of patients like Ms. Lanoux survive five years. The median survival rate is one year.

"It's hard to see most patients die," Dr. Hwu said. "You look at patients and see yourself and your family. We have to keep focusing on making these treatments better."

On Wednesday, Ms. Lanoux was admitted for her eighth cycle of biochemotherapy. Dr. Hwu was worried.

“I don’t think her body will tolerate many more cycles,” he said. Already he has had to reduce the doses of some of the drugs and eliminate others.

In the meantime, he makes calls nearly every day, trying to get the experimental drug for Ms. Lanoux.

“We’re on the front lines,” he said. “We need armor.”

“I need this drug, and I need to be able to offer it to her.”

A View From Both Sides

As a breast cancer nurse, Cindy Davis thought she knew what her patients were going through. Until she went through it herself.

The first time she had a [mammogram](#), it found cancer. She was 43. But after a [lumpectomy](#), radiation and hormonal treatment with the drug tamoxifen, she was cancer free. The statistics were with her. She had every reason to think the cancer would not come back.

And that helped because she had taken a nursing job in the breast cancer clinic at Anderson, working with many patients pretty much like her — their cancer had been caught early, they would be fine.

Then, last April, nine years after the diagnosis, her cancer came back in a pelvic bone.

“You never think it is going to happen to you,” Mrs. Davis said. “I look at the risk factors, and I have none of them. It’s like, ‘Wait — I did everything right.’ ”

“I did the denial thing, 100 percent,” she said. “And I was angry. No, no, it can’t be that. And I was in shock — you’ve got to be kidding.”

As a nurse, she knew all too well there is no cure for breast cancer that has spread beyond the breast. Two-thirds with advanced disease are dead within five years.

“When you know what I know, it’s very scary,” Mrs. Davis said.

Her chemotherapy began a few days after she learned that her cancer had spread.

“I was scared; I was very scared,” Mrs. Davis said. “I know all the possible things that can go wrong.”

To her surprise, it was uneventful. Three weeks later, she and her husband went on a cruise. Just before it was over, her hair fell out.

“I got out of the shower and started combing my hair and it was coming out,” she said. “I started crying. Everyone says, ‘It’s just hair. It will grow back.’ But as women, that’s a big thing to us.”

Devastated, she got a wig and, feeling very self-conscious, went back to work. She has been working ever since, taking most of the week off after each chemotherapy treatment to recover from nausea and overwhelming fatigue. So far she has had 17 treatments, with more to come.

She is a nurse by day in the fifth-floor breast cancer clinic, and a patient in the evening, going to the eighth floor for chemotherapy. There she sees many of the women who were in the clinic earlier.

"It's like a club," Mrs. Davis said. The women talk about side effects — [mouth sores](#) and damage to the nerves of their feet — and the nausea and the anticipatory nausea.

"I have patients who say, 'I just see a hospital gown and I feel nauseated,' " Mrs. Davis said. "I didn't understand it before."

She also asks patients for help, turning to those who learned they had advanced breast cancer two, three, four years ago.

"I say, 'How do you do it?' " Mrs. Davis said. "They say they pray a lot and they just do it. They get through it one day at a time."

Working at Anderson while being a patient there means cancer is always on her mind.

"You are around it all the time," she said. "It's just so hard to shut it off when you go home. Now I find myself thinking more and more about patients. I pray for them, and they hug me and say they are praying for me."

She ran into a patient's mother recently. The patient, a young woman, had advanced breast cancer and was terrified. Mrs. Davis told her she had advanced breast cancer, too, and she would help. "I am your nurse," she told the young woman.

The mother came up to Mrs. Davis and said: "You have no idea how you have impacted this family. You gave my daughter hope that she could get through this."

An Opponent That Won't Quit

Dr. Raber used to think he understood when his patients told him that their appetite was good or that they were feeling more energetic.

But now, a cancer patient himself, he talks to patients in a very different way.

In the old days, if a patient said she had a good appetite, he would interpret that to mean her appetite was the same as his. Now he asks different questions.

"What did you have for lunch?"

"Crackers and soup."

"What did you have for dinner?"

"Crackers and soup."

"What did you have for breakfast?"

"I don't eat breakfast."

"Patients who say their appetite is fine often are saying it is better than it was," Dr. Raber said. "They are not saying it is anything like the appetite of a healthy person."

The same goes for energy level.

"When I came home from the hospital when I had been really, really sick, I was able to walk down the stairs once a day and up the stairs once a day. After I had been home for a couple of weeks, I could walk up and down

maybe twice. If a doctor had asked how was my energy level, I would say, 'Great, much better,' " Dr. Raber said. "The doctor would assume it was the same energy level as his."

Dr. Raber's journey as a cancer patient began in 1996, when he was 48 and physician-in-chief at Anderson. "I was at the top of my game," he said.

A routine exam showed abnormalities in liver function tests. He thought it was nothing, waited six weeks, and had the test again.

The results were still abnormal. His internist suggested a CT scan, but neither Dr. Raber nor his doctor was concerned.

While Dr. Raber was on the table, the radiologist came in and said, "You have a problem." There was a mass near his liver.

"This is serious," he thought. "I figured, 'This is early November. I could be dead by Christmas.'"

His doctor scheduled a biopsy for later that day.

That afternoon, after the biopsy, the pathologist told Dr. Raber he thought it was melanoma.

"I said to myself, melanoma. I could be dead by Thanksgiving," Dr. Raber said.

It turned out to be lymphoma, a tumor of the lymphoid cells of the immune system, which is easier to treat and even cure than [liver cancer](#) or melanoma.

But treatment, with chemotherapy and radiation, made it impossible for Dr. Raber to work full time. At best, he could manage a few hours a day. He was ill, he was tired, and, he said, "My brain was scrambled."

He stepped down as physician-in-chief. He no longer saw patients.

Two years later the cancer was back, in the same place. Once again he had aggressive chemotherapy and radiation. Two years after that, his kidneys failed. He spent time in the intensive care unit.

He did not work for a year, spending most of his time on the sofa. His lower body filled with fluid. His 32-inch waist ballooned to 52 inches. His size 9 1/2 foot became a 12. All he could wear was a sweatsuit and slippers.

Finally, he went back to work for an hour, two or three times a week. And he went back not as an administrator but as a doctor and a teacher, "an earlier iteration of myself."

In February, he got another cancer, melanoma.

By now he has gotten used to living with cancer.

"It just becomes your life," Dr. Raber said. "You come in, you have tests, you go home, you do your thing, you come back again for treatment.

"I tell patients, 'It used to be that you had cancer, you got treated, you died or you were cured,' " he said. "Now, for most of us, it's a chronic illness. It's not a question of being psyched up: I will have this surgery and then I will be cured. The disease comes back."

He works part time, seeing patients on Tuesday and Thursday mornings and spending a day a week working at a clinic in the county hospital.

“A common question people would ask is ‘Are you a better doctor since you’ve been sick?’ ” Dr. Raber said. “My first answer is that I thought I was a good doctor before. I was worried about being a worse doctor. Having lived through these biopsies and all these tests, would I be hesitant to order all these things patients need because I had experienced them and knew they were not pleasant?”

“Then I realized I am not better, but I am a different doctor,” he said. “I talk to patients differently. I understand more of what their situation might be.

“My life was very different than it was before that day in the CT scanner,” Dr. Raber said. “It’s not the life I thought I would have. But my life is still really good.

“My son is fond of saying, ‘It is what it is.’ That’s true. This is my life. I enjoy it a lot. It works out well for me.”

As for winning the war on cancer, Dr. Raber, on the front lines, has his own thoughts. “We are making a lot of progress,” he noted.

But “are we there yet?” he asked.

“Not even close.”

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