NON-CIRCULATING

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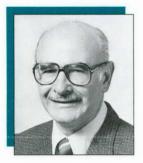
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MD Anderson Oncolog

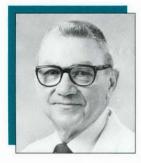
Technique, widely used in Europe, gaining new ground in U.S.

Rotationplasty: an alternative that approaches limb salvage

Treatment Update



Norman Jaffe is a professor of pediatrics in the Department of Pediatrics



John Murray, a professor of surgery, is deputy head, Division of Surgery and Anesthesiology

Rotationplasty, a turnabout procedure that uses the ankle as a knee joint to control a conventional prosthesis, is a viable option to amputation in children with osteosarcoma. Although oncologists hope that chemotherapy and surgical resection will allow limb salvage, a procedure that replaces the resected bone with a metal endoprosthesis or bone graft to "save" the limb from amputation, Norman Jaffe, M.D., D.Sc., acknowledges that a middle or distal osteosarcoma of the femur at times dictates amputation. Jaffe, a pediatric medical oncologist at The

University of Texas M. D. Anderson Cancer Center, said that, for some patients, the best option is rotationplasty, which he describes as "a modification of amputation that approaches limb salvage."

Limb salvage is not always a possibility. "It is the child's response to preoperative chemotherapy," emphasizes John A. Murray, M.D., deputy head, Division of Surgery and Anesthesiology, "that dictates what the surgeon can do." "Osteosarcoma," Murray

said, "notoriously occurs as a large lesion that frequently fractures the bone. The actual involvement of a neurovascular bundle by the tumor precludes reconstructive limb salvage. While osteosarcoma usually displaces vital structures as it expands, it occasionally encases them, risking the quality of the resection and the limb salvage." Although M. D. Anderson performs needle biopsies for diagnosis, it still receives children for treatment who have undergone open biopsies at other institutions. These open biopsies, Murray says, severely limit the quality of limb salvage. "Furthermore," he adds, "limb salvage can't overcome an infected tumor that indicates amputation."

Rotationplasty, developed by J. Borggreve in 1930 for the treatment of severe tuberculosis of the knee and applied by C. P. van Nes in 1950 in the treatment of congenital limb shortening, removes the cancerous end of the femur while preserving the neurovascular bundle. The tibia is then rotated 180° and attached to the stump of the femur, thus con-



verting the heel to a "knee." Because the foot and heel is so powerful, Jaffe explains, "an above-the-knee amputation is converted to a below-the-knee amputation." Lynda S. Jackson, senior physical therapist at M. D. Anderson Cancer Center, points out the primary advantage of rotationplasty over amputation: "The longer the lever arm, the easier it is to manipulate the prosthesis and to walk." Indeed, rotationplasty has some advantage over arthrodesis, a procedure that fuses the knee joint to pro-

duce a stable but inflexible limb that limits the child's activities.

Rotationplasty is a particularly functional option in a very young child whose skeletal growth will cause a salvaged limb to be as much as eight or ten inches shorter than the normal limb, limiting the child's ability to walk. The Lewis expandable adjustable prosthesis, an endoprosthesis that can be lengthened as the child grows, has attempted to overcome this limb-length discrepancy. Murray cautions, however, that this **continued on page 2**

Perspectives of two mothers

✓ate Jordan, mother of six-year-old Michael (left), explains why rotationplasty was

the best choice for her son, who has recently undergone treatment for osteosarcoma: "We felt rotationplasty was an alternative to Michael having an abovethe-knee amputation. It gives Michael mobility that people with an artificial knee don't have-like climbing stairs, playing sports, dancing, and 'chasing girls." Julie Perez, mother of five-year-old

Al (right), who also has a rotationplasty, adds that young children with endoprostheses seem to have more problems and are not as mobile.

Both mothers concede they have had ambivalent reactions from the public. "If you

can get over the initial

fear of having a child with an altered limb that someone would not normally see," Jordan says, "the rewards are fantastic. Never once have I regretted the decision." Perez concurs, "Anyone can see how well the children are doing." Although adults seem hesitant, Perez says that the children accept the changed limb. Her son

Al has told his mother several times that he is glad he still has part of his leg: "And," she concludes, "that has made a lot of difference to him."

mechanical spacer is "not very sound mechanically." He considers this lengthening device to be a "stopgap measure" that will eventually fail: "Enormous forces pass through bone. One of the beauties of bone is its capacity to withstand these forces and, indeed, to adapt to them. If a piece of metal is inserted into the limb and held by plastic to the bone, it is strongest the second it is put in, and every minute from then on, it is weakening." The same forces that loosen a conventional prosthesis act on an internal device that is much weaker, resulting in the risk of repeated surgeries for the child. Although some families wish to "try out" the expandable prosthesis with the hope that subsequent operations can increase the functionality of the limb, Murray explains that each surgical procedure increases the incidence of complications from scar tissue and decreases the ability of the tissue to expand until "the burden of these procedures produces an extremity that is less functional than an amputation." A salvaged limb limits a child's athletic activities to those that will not put the endoprosthesis at risk. On the other hand, a child with a rotationplasty can participate in sports-from skiing to soccer. In cases in which limb salvage is contraindicated, Murray strongly encourages a rotationplasty: "It is so functional, and after healing, it is permanent."

Jaffe acknowledges that families-as well as physicians-are reluctant to choose rotationplasty because of the unusual appearance of the resected limb. Although Jaffe has recommended the option to ten patients, only four have concurred. Parents find the "pseudoknee" to be cosmetically unattractive, although the foot is covered with an external prosthesis. Apparently, the procedure is more accepted in Europe, Jaffe said, where children remove their prostheses to swim in public pools.

To prepare the child for rotationplasty, a pediatric team-composed of health workers from medical oncology, surgical oncology, child life, social work, psychology, nursing, and physical therapy-works out a plan of functional and psychosocial treatment to help the child accept the procedure and learn to cope. Donna R. Copeland, Ph.D., clinical psychologist, explains that "amputation involves a physical and psychological loss. Such a loss affects a child's self-image and self-esteem. Strengths in these areas can be regained by supportive relationships with those around the child and through mastery of tasks and accomplishment of goals." Copeland confirms that "ultimately, the child can feel independent and retain a



Sheila Brown (center), child life specialist, uses the amputee puppet Paul to initiate a medical play session with Michael Iordan (left) and Al Perez (right), two young patients who have recently undergone rotationplasty at The University of Texas M. D. Anderson Cancer Center, Paul's leg can be "amputated" to a stump, and his ankle and foot can be reattached into the turnabout position of a rotationplasty. The two boys give Paul "inoculations" and "take his blood." Michael and Al decide whether Paul swallows his pills or spits them up, hides his face beneath his hand or talks about what life will be like after the rotationplasty procedure.

cohesive body image."

Patricia L. Adams, pediatric social worker and primary mental health worker at M. D. Anderson, said, "Planning comprehensive trea-ment from the time of the first diagnosis is essential." During the "anticipatory grief process" before surgery, the child needs time to grieve for the loss of the limb and needs to have very accessible support, Adams said. Preparation for the rotationplasty must be determined by the child's style and the amount of information he wants. A framework for candid talk about what life will be like after the rotationplasty needs to be constructed. Adams said that younger children's talk focuses on function. A young child, concerned with his later ability to run, jump, and play, asks, "Can I play baseball?" A teenager, she indicated, worries more about appearance and thus is encouraged to talk with another teenager who has undergone the procedure. Friends and siblings are invited to visit M. D. Anderson. An education coordinator is available to visit the child's classroom to explain to his peers what is happening. However, the wish for privacy is equally honored.

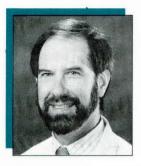
Adams underscores the child's need to exercise control over his life. Therapeutic play not only relays information to the child but helps him perceive he still has some control. Kimberly H. Riemer, child life coordinator, explained that medical play before the child undergoes surgery makes rotationplasty more concrete and allows the child to practice the procedure on a puppet. A pink, amputee puppet named Paul is used by child life specialists to help young children form a concept of what life with a stump will be like. The child changes the dressings on Paul's stump and rotates Paul's leg into a turnabout position. Riemer points out that the child's manipulation of the puppet's stump coupled with an opportunity to discuss his feelings reduces the threat. Teenagers "play" with a more technical Zadie doll. After the child "experiences" rotationplasty through medical play, he begins physical therapy. Physical therapist Jackson likes the child to practice with crutches when he is pain free, before the procedure. This practice, she proposes, not only prepares the child for functional rehabilitation but also reduces his fear of the procedure.

After surgery, the pediatric team helps children adjust to their loss as quickly as possible, with the ultimate goal of seeing themselves as normal. Gait training using crutches to walk on flat surfaces begins on the first day following surgery. By the second or third day, the child is taught to deal with stairs and other architectural barriers found in public life. As soon as feasible, a program of muscle strengthening to increase endurance is initiated. Jackson adds that it is important to focus the children on what the rotationplasty allows them to do, activities such as playing soccer and climbing stairs. She helps the kids feel proud of pulling on their prosthesis: "It's their leg."

Copeland explains that a crisis time occurs when the recommendation for amputation is first made and again sometime later after the rotationplasty: "Immediately following the surgery, the child usually recovers quickly. Everyone is pleased but should be prepared for the possibility that the child may experience a period of depression some weeks later when facing the reality of loss and its implications." For this reason, the pediatric team at M. D. Anderson continues **continued on page 7** Protocol allows more patients to complete therapy

Chemoradiation protocol maintains control rates, has fewer toxic effects

Treatment Update



Tyvin A. Rich is a professor of radiotherapy in the Department of Radiotherapy

The obstacles to cure cancer most often lie in the tumor's unresponsiveness to treatment, but at times the problem rests with the toxicity of the treatment itself. For some patients, the probability of cure using current therapy is good, but only if they can complete treatment before serious complications arise. This issue is of particular concern to Tyvin A. Rich, M.D., a radiotherapist at The University of Texas M. D. Anderson Cancer Center. In collaboration with Jaffer A. Ajani, M.D., William H. Morrison, M.D., David M. Ota, M.D., and Bernard Levin, M.D., Rich redesigned a drug schedule for irradiation and 5-fluorouracil (5-FU) with and without cisplatin. The goal was to reduce toxic effects so that all their patients with anal cancer could complete therapy. After one year of minimum follow-up, their modified schedule had not only resulted in an 89% local control rate of anal cancer with all patients completing treatment but had produced no serious late complications. Although Rich quickly points out that a five-year survival mark has yet to be reached, the preliminary results indicate a late complication rate lower than that produced by other published dose schedules.

Like most antineoplastic agents, radiation therapy and chemotherapeutic agents have a therapeutic in-

dex. Oncologists often work within a "narrow window" between tumor control and complications. Because radiation oncologists push the limits to cure patients, Rich said that "we accept a small but real complication rate in late-responding tissues of anywhere from one to five percent. If we weren't pushing it, maybe we wouldn't have any complications, but we would certainly cure fewer patients."

With the antimetabolite 5-FU, balancing the dose needed for tumor control against the dose that avoids ulceration is a fine line. Oncologists have an additional concern: the schedule of administration also affects the dose-limiting toxicity of 5-FU. For example, continuous-infusion regimens are generally limited by gastrointestinal mucositis, while bolus schedules are limited by bone marrow suppression. Complications are further increased when radiotherapy is combined with either method of administration. Outlining both the advantages and the disadvantages in combining radiotherapy and chemotherapy into a treatment modality known as chemoradiation, Rich explains: "Chemoradiation ideally should be designed to exploit cytotoxic cooperation between modalities that have little or no overlapping toxic effects; however, the dose-limiting toxic effects seen with chemoradiation result in treatment effects much like those of radiotherapy using accelerated fractionation schedules." Radiation oncologists, faced with the effects of toxicity, have historically examined ways to make treatments effective against the cancer while minimizing toxic effects.

One way to reduce toxicity is to divide the total radiation dose needed to obtain tumor control into frequent, small doses. "Since the early days of radiotherapy," Rich explains, "it has been apparent that better results can be obtained when the total radiation dose is fractionated into small increments rather than delivered as a single dose or in a few large doses." Rich links what can be observed in the clinic to a radiobiologic model: "This empiric discovery now is supported by modern radiobiology's appreciation of

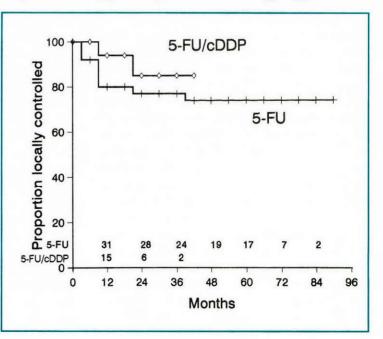


Figure 1. Local control of anal cancer using chemoradiation protocols of The University of Texas M. D. Anderson Cancer Center.

"A preliminary analysis suggests that [our] late complication rate is lower than anyone else's"

the radiation dose–survival curve and, in particular, by an understanding of the importance of repair and repopulation in normal tissues and tumors." This insight not only has helped explain why acute and late effects are observed but has also aided the design of newer radiotherapy trials.

For chemoradiation, Rich observes, most institutions deliver bolus chemotherapy as a rapid injection in a "big, single fraction," whereas continuous infusion chemoradiation schedules are akin to daily courses of fractionated radiotherapy. This latter type of combined-modality treatment fractionates radiotherapy into a series of five-day courses combined with "fractionated" chemotherapy. The value of these types of chemoradiation schedules is now becoming evident, says Rich. While using radiation plus 5-FU with or without cisplatin to treat 58 patients with anal cancer, the M. D. Anderson team focused on controlling immediate toxic effects so that all their patients could complete treatment in the outpatient setting. Radiotherapy dosing was modified to reduce acute effects by decreasing the dose to the anterior and posterior irradiation fields from a total dose of 45 Gy to 30 Gy in 1.8 Gy/day fractions and by excluding the small bowel from the radiation portal by using a specialized treatment positioning. After the patients received the

30-Gy dose, they received a three-field irradiation plan (a single posterior field and two lateral, wedged fields) to a total dose of 55 Gy. After analyzing the effects of 5-FU chemoradiation in the initial 25 patients, the team further modified the chemotherapy schedule with radiotherapy from a seven-day/week schedule to a fiveday schedule. Next, they added continuous infusion cisplatin to the five-day schedule of 5-FU. In the current treatment program with double chemotherapy and radiotherapy, a mean 5-FU dose of 10.8 g and a mean cisplatin dose of 188 mg were administered over 42 days.

Unlike an earlier M. D. Anderson study in which acute toxic effects required an interruption in radiation therapy in 29% of the patients and a discontinuation of 5-FU infusion in 40%, all 18 patients receiving double-agent chemotherapy were able to complete treatment. (The previous study used a seven-day 5-FU infusion of 300 mg/m²/day combined with total radiation doses between 46 and 60 Gy). The M. D. Anderson team found that despite the reduction in total dosage of both radiation and chemotherapy, an 89% local control rate was obtained with the fractionated double-agent chemoradiation

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Site	Treatment	No.	Grade ^a			
			1	2	3	4
Skin	Present series	58	2%	-	-	-
Subcutaneous (anal canal)	Present series	58	9%	22%	-	-
Rectal	Present series	58	22%	9%	-	-
Bladder	Present series	58	-	-	-	-
Anal/rectal	Radiotherapy alone ^{b,c}	212	-	-	-	0-23% ^d
Anal/rectal	Chemoradiation 5-FU +/- mitomycin ^b	125			10–65%	6–25% ^d

Table 1. Late radiation complications for the 58 patients treated with chemotherapy

^aRadiation Therapy Oncology Group's late-effects criteria. Winchester DP, Cox JD. CA Cancer J Clin 42:135–163, 1992.

^bCummings BJ. Front Radiat Ther Oncol 26:131–141, 1991.

^cShank B. Cancer 55:2156-2162, 1985.

^dSevere necrosis, requiring surgery.

Patient Advocacy continued from page 8

ground. We try to educate patients about what the institution can and cannot reasonably provide. We frequently uncover potential roadblocks to M. D. Anderson's commitment to excellent service. If we find that policies or procedures are getting in the way of patient satisfaction or customer service, we'll push to get them changed," Bean said.

"Sometimes there is a gap between perception and reality, and when a patient tells the doctor, 'I will not do that; you can't make me,' the doctor becomes frustrated because communication with the patient has reached an impasse. Such an occurrence frequently prompts both patients and doctors to contact Advocacy," said Bean.

Some patients who come to Patient Advocacy state that it is their right to be treated the way they want to be treated. Bean's typical reply is, "Yes, it is. But it's also your physician's right to practice what he or she considers to be good medicine. They can't compromise on that."

She related a frequent scenario: "A patient comes in and says, 'I want you to change my doctor.' And we listen. We do a lot of listening, but we also ask whether the patient has shared his or her concern with the physician." In most cases, Bean said, the patient hasn't. In fact, since she started the Patient Advocacy program 8 years ago, Bean said she is aware of only one instance in which the patient confronted the doctor before seeking help from Patient Advocacy.

"Obviously," she continued, "if a patient were comfortable with going directly to his or her physician and saying, 'Look let's talk about this,' then we would not need Advocacy. The reality of the world is such, though, that that's not going to happen." She surmised that part of the reason patients do not confront their doctors directly is that they fear that, by voicing complaints or questions, they will alienate the caregivers they depend on for treatment.

Advocates encourage doctor/patient communication

Thus, the usual next step is to encourage the patient to speak directly with the caregiver. "I tell them," Bean said, "that unless your physician knows that your needs are not being met, you have very little chance of getting your needs met. We then embark on what can be a lengthy process of educating patients to share their feelings with the physician or other caregiver in a reasonable way."

Bean said that how a hospital approaches the subject of patients' rights is now part of every hospital's accreditation. However, M. D. Anderson had a patients' rights statement long before the Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) mandated that they develop one. A few years ago, Bean and several co-workers updated M. D. Anderson's existing patients' rights statement, following JCAHO standards and requirements and presenting the necessary information in clear, friendly language. The Patient Rights policy is written on a sixth-grade reading level and is printed in both English and Spanish. The policy begins with a brief two-paragraph statement that explains M. D. Anderson's view of the partnership and the reasoning for the policy statement. The document also states M. D. Anderson's mission.

More staff needed

Patient advocates visit with as many patients as possible every day. However, simple arithmetic shows that the four current patient advocates—Bean, Joan Arnim, Elaine Crump, and Michele Walker—face an almost impossible task of serving the more than 2,000 outpatients and the approximately 520 inpatients seen at M. D. Anderson every day. To help with the demand, Bean developed a program of volunteer patient advocates.

Volunteer patient advocates visit with hospitalized patients to find out about their level of satisfaction. The volunteer's involvement is welcomed by patients, families, and M. D. Anderson staff. Volunteer patient advocates do not handle any problems that involve personnel, but they are trained to pursue and resolve all other problems that may arise and to report their visits with each patient and any actions taken to Patient Advocacy.

Because the volunteer program is new, Patient Advocacy is still undermanned. However, Arnim, assistant director of Patient Advocacy, says that they are very pleased with the M. D. Anderson volunteers who participated in the recently developed and piloted program to become volunteer patient advocates. In planning the training of future volunteer patient advocates, Arnim will incorporate suggestions from the first participants. Patient Advocacy also plans to extend the services of the volunteer force from the first tested inpatient units to all areas of the hospital.

Bean and Arnim agree that the greatest benefit of creating the volunteer force is that Patient Advocacy can extend its reach to all patients who come to M. D. Anderson. "For patients and staff, Patient Advocacy is an around-the-clock resource of people who will listen, investigate, intervene, and mediate problems that impede the quality of patient care and diminish patient and staff satisfaction," Bean said. An unattributed saying displayed prominently in Bean's office echoes one philosophy of patient advocates: "The single most important act of caring is listening."

The 24-hour service provided by Patient Advocacy and the increase in the department's human resources because of volunteer patient advocates enable patients and staff to talk and have someone to listen and, when necessary, to take action in their behalf.

—KIMBERLY JT HERRICK

Physicians who desire additional information may write Leslie Bean, Department of Patient Advocacy, Box 111, The University of Texas M. D. Anderson Cancer Center, 1515 Hol-combe Boulevard, Houston, Texas 77030, or call (713) 792–7776.

Rotationplasty continued from page 3

comprehensive care of long duration.

Jaffe coordinates a yearly amputee ski trip to Park City, Utah, to "enhance functional rehabilitation and encourage psychological adaptation to amputation." By learning to ski, children with rotationplasty achieve something that most people with two legs have not accomplished. M. D. Anderson's Camp AOK and Camp Star Trails involve the children in active outdoor experiences-swimming and horseback ridingwith peers and siblings. Trips to Austin, Disney World, and Washington D.C. teach practical "getting around" techniques in the public world while promoting psychosocial adaptation. Many patients return to talk to new patients at birthday parties and to participate in field trips. Murray points out that children do well after rotationplasty: "The adaptability of children is enormous."

Agreeing with Murray, Jaffe adds, "A rotationplasty has extricated the tumor, retained the good muscle and bone from the site beyond the tumor, and is functionally an extremely good mechanism for climbing stairs, playing football, dancing, and walking."

-LINDA EPPICH

Physicians who desire additional information may write Dr. Norman Jaffe, Department of Pediatrics, Box 87, or Dr. John Murray, Division of Surgery and Anesthesiology, Box 106, The University of Texas M. D. Anderson Cancer Center, 1515 Holcombe Blvd., Houston, TX 77030, or call (713) 792–6626 (Jaffe) or 792–8828 (Murray).

Chemoradiation

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(Figure 1, p. 4). Furthermore, an analysis of late complications showed that, just as radiation dose fractionation increases the tolerance of tissues to radiation therapy, chemotherapy fractionation, when combined with radiotherapy, seems to increase the tolerance of late-responding tissue for chemoradiation, thus significantly widening the therapeutic window.

Although the purpose for fractionating chemotherapy had been to reduce immediate toxic effects, the team unexpectedly observed no serious late effects of anal fibrosis, stricture, or necrosis. This contrasts markedly with chemoradiation using short, daily, highdose 5-FU schedules alone or in combination with mitomycin, which result in late grade 3 and 4 complication rates of 6–65%. Cautioning that a five-year mark has not yet been reached, Rich says, "A preliminary analysis suggests that the late complication rate is lower than anyone else's" (Table 1).

Rich suggests that the results from lower total doses of radiation and five-day fractionation of chemotherapy indicate that radiotherapists should reevaluate conventional wisdom: "To maximize cure, most radiation therapists use a total radiation dose based on late tolerance." Because the M. D. Anderson team achieved such a high local control rate and low late complication rate when radiation doses were reduced from total doses of 60 Gy to 54-55 Gy in combination with 5-FU plus cisplatin, Rich suggests that therapists may be able to "dial back" radiation dosage levels: "The total doses of radiotherapy, when combined with chemotherapy, were below what would classically be used with radiotherapy alone. As we choose different chemotherapeutic agents, the balance between dose levels of radiotherapy and chemotherapy may need to be reexamined."

The exciting possibility arising from these observations, Rich hypothesizes, is the formulation of a model that may explain how fractionation of chemotherapy may help widen the therapeutic window by improving the control curve while having a small effect on the complication curve.

-LINDA EPPICH

Physicians who desire additional information may write Dr. Tyvin A. Rich, Department of Radiotherapy, Box 97, The University of Texas M. D. Anderson Cancer Center, 1515 Holcombe Blvd., Houston, TX 77030, or call (713) 792–2972.

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Inside

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Patient Advocacy nurtures partnership between caregivers and patients

Patients



Leslie Bean is director of Patient Advocacy

When people become patients, they hand over much personal control of their lives to the dictates of healthcare policy and providers. Because so many issues—cost, diagnosis, family, and prognosis—are involved in treating illness, especially long-term illness, it is important that all immediately concerned with each situation know what they can expect from the caregivers and what the caregivers expect in return.

The responsibility for treating patients with dignity lies with healthcare providers, and to maintain trust, these providers must help patients understand and cope with the realities of the system into which they are thrust. Departments such as M. D. Anderson's Patient Advocacy exist to provide patients with the information and help needed to maintain a sense of control over their personal lives and to understand their rights and responsibilities and those of the institution.

"Advocacy's primary focus is on patient and family confidence and satisfaction. We help to personalize a system that can be overpowering. A patient comes to Advocacy because he or she has a specific problem that needs to be resolved and isn't sure how to approach it," said Leslie Bean, director of Patient Advocacy.

As one of four patient advocates, Bean has the responsibility of mediating patients' concerns, whether those concerns are based in fact or born of frustration and anger. Bean explained, "Cancer is enormous—physically, psychologically, financially—and there is much fear and anger associated with it. We try to deal with these feelings in a positive way to increase confidence."

Bean explained that sometimes a patient's general fury about the illness becomes unjustifiably focused on the caregivers. Other times, a patient's anger is based on a legitimate complaint. For patient advocates, the impetus of the complaint is not the issue. Their role is to listen to the patient and to provide him or her with alternative ways to address or resolve the problem. "We don't offer advice; we don't counsel. We help patients see what their options are; we act as mediators," Bean said.

Acting as mediator can be difficult, though. "We walk a very fine line: we advocate for the patient and the institution, and we try to maintain common