

An Interdisciplinary [A Model Indiana Outpatient Clinic Program] to Cancer

A new cancer rehabilitation program at Saint John's Health System in Anderson, Ind., is helping to restore the strength and endurance that patients with cancer lose as a result of radiation, chemotherapy, and the cancer disease process. Conquering fatigue, weakness, range of motion deficits, and daily living issues gives patients renewed control over their lives, helps them restore normal functioning, and allows them to go from victims to survivors.

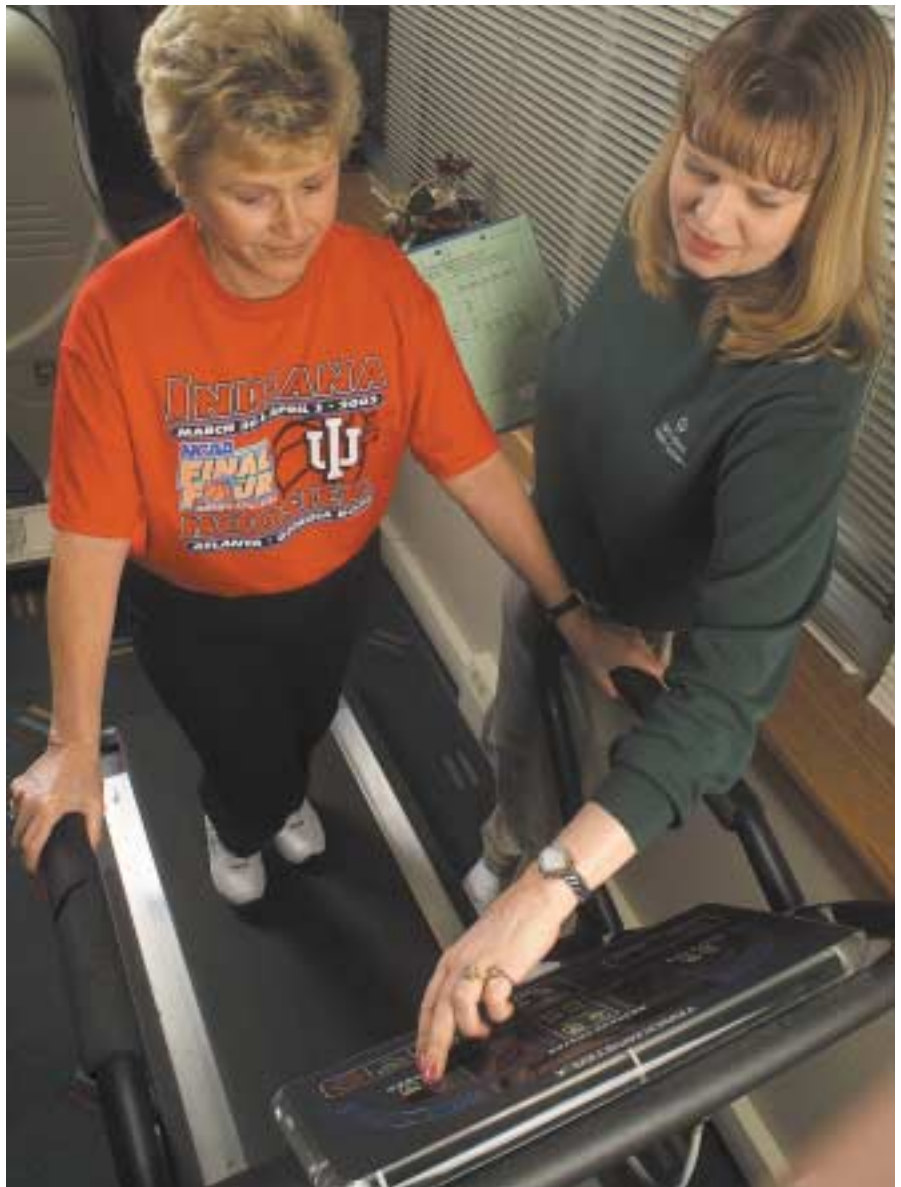
The Role of Rehabilitation in Cancer Care

Rehabilitation in cancer originated with the National Cancer Act of 1971, which declared cancer rehabilitation as an objective and directed funds toward the development of training programs and research projects.

The following year, the National Cancer Institute (NCI) identified four objectives in the rehabilitation of cancer patients: 1) psychosocial support, 2) optimization of physical functioning, 3) vocational counseling, and 4) optimization of social functioning. During the 1970s, the NCI initiated and supported a number of model systems for cancer rehabilitation programs.¹

Four categories of cancer rehabilitation have been recognized² and should be included in all cancer rehabilitation programs:

- *Preventive* efforts educate patients, reduce the impact of expected disabilities, and identify patient issues and concerns that may require professional intervention.



Better mobility of the shoulder was the physician's number one goal for patient Irene Pancol (at left), so she could tolerate the treatment position for her radiation treatment. Although this goal was also important to Irene, her priority was to rebuild her endurance to allow her to climb up and down the bleachers to watch her IU Hoosiers play basketball. She succeeded through participation in the program and with assistance from her PT Julie McCormack, shown here at right.

Approach Rehabilitation

by Julie A. McCormack, P.T.

- *Restorative* techniques attempt to restore patients to previous levels of physical, cognitive, and psychological functioning.
- *Supportive* efforts focus on helping patients compensate for and/or minimize disabilities, and provide emotional support while the patient adjusts to lifestyle changes after cancer.
- *Palliative* techniques increase the patient's comfort level by minimizing or eliminating complications. Palliative services include pain management, prevention of contractures, prevention of unnecessary deterioration from inactivity, and psychological support for the patient and family members.

Physical, occupational, and speech therapies can address all four rehabilitation categories through education, exercise, endurance activities, recommendations for adaptive equipment, and pain control techniques. Nausea and fatigue are reduced as well.

Developing an Interdisciplinary Rehabilitation Program

The Saint John's cancer rehabilitation program grew out of a collaborative effort between the Saint John's outpatient cancer treatment center and the Saint John's outpatient rehabilitation clinic, The Carl D. Erskine Rehabilitation and Sports Medicine Center. Since the program's inception in December 2000, the staff has worked in partnership to develop a comprehensive program. Today, cancer rehabilitation services are provided by five members of the outpatient clinic staff, including physical therapists, physical therapy assistants, occupational therapists, and speech therapists.

The first step in developing the cancer rehabilitation program at Saint John's was to conduct an extensive literature search regarding the kinds of physical activity involved in cancer rehabilitation. The search revealed a range of useful activities, from walking to combinations of aerobic exercises and strength training. The American Cancer Society finds regular physical activity critical in preventing some types of cancer, and both the Centers

The Big Three in Rehabilitation Staffing

The *physical therapist* (PT) is trained to test muscle strength, range of motion, sensation, balance, gross motor coordination, and endurance. If limitations are noted in any of these areas, the PT develops treatment strategies and works with the patient to correct, improve, or compensate for each limitation. Exercises might include general strengthening, gross motor control, balance retraining, and endurance activities. PTs determine whether devices can help patients walk safely. Specially trained therapists use manual techniques for decreasing soft tissue restrictions, minimizing scar tissue tightness, and assisting in the drainage of the lymphatic system when lymphedema occurs.

The *occupational therapist* (OT) evaluates the patient's ability to perform activities of daily living (ADLs), and determines the need for adaptive equip-

ment that will allow patients to complete tasks more safely or more independently. Exercises might be focused on strengthening the upper extremities, increasing standing endurance, and developing fine motor control to make ADLs more manageable. Adaptive equipment might include reachers and lower extremity dressing aids if range of motion is limited. Splints may also be used to limit joint contractures in cases of progressive fibrosis. The OT also evaluates visual perception and cognition deficits that interfere with ADL performance, designs activities to correct or compensate for these problems, or makes appropriate referrals.

The *speech therapist* is trained to evaluate any difficulties in speech or swallowing functions and help patients exercise and retrain the muscles that cause such problems. Speech therapists also advise patients on how to prepare food when swallowing difficulties exist, recommending changes in the serving size or temperature of food, and compensatory positioning techniques such as the chin-tuck position to protect the airway from aspiration of food and drink.

for Disease Control and Prevention and the National Cancer Institute have linked exercise to the prevention of colon cancer. Exercise also plays an integral role in cancer treatment. Several studies show outstanding outcomes for patients who include exercise as part of their cancer therapy, as well as for patients who exercise following completion of treatment.^{3,4,5,6} Common benefits after exercise include decreased fatigue, nausea, and pain and improved strength, endurance, general mobility, and quality-of-life satisfaction.^{3,4,5} Most patients indicate that they regained control over their lives with active participation in these programs.⁴

Rehabilitation treatment most often includes low-level endurance training, general mobility training, activ-

ities of daily living (ADL) training, range of motion exercises, and strengthening specific to limitations (See Table 1). Education is a large part of treatment and may include information on general safety, energy conservation, task simplification, relaxation, and stress management. Most patients attend therapy two or three times a week for three to four weeks. Many patients meet their goals much earlier and are released to continue home exercise programs.

The literature search also revealed that a number of rehabilitation programs use standard plans of care and structured endpoints to measure success. These care plans varied among programs, but included one of the following: timed walking,³ distance measured walking,⁵

Table 1: Rehabilitation Treatments for Seven Functional Limitations Experienced by Cancer Patients

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|---|--|--|
| <p>1 <i>Post-radiation or chemotherapy weakness limiting ADLs</i></p> <ul style="list-style-type: none"> ● Gentle warm-up activity (i.e., riding a stationary bicycle, walking on a treadmill) ● Strengthening exercises seated in chair (i.e., knee lifts, knee extensions, ankle active movements, bicep curls, overhead reaches, wrist and hand exercises, grip strengthening) ● Strengthening exercises laying on mat (i.e., leg raises, bridges, bench press, abdominal strengthening) ● Strengthening exercises in standing position (i.e., squats, heel raises, marching, hip exercises) ● Progression to small weights or light resistance bands as tolerated for each strengthening exercise ● Education regarding safe progression of exercises, modification of ADLs as needed, and instruction in use of adaptive equipment as indicated | <p>ADLs, if possible</p> <ul style="list-style-type: none"> ● Education regarding importance of maintaining activity level or building upon current level daily | <ul style="list-style-type: none"> ● Assist with fitting of proper compression garment ● Education regarding prevention of infection or exacerbation of lymphedema |
| <p>2 <i>General decreased endurance during or after cancer treatment</i></p> <ul style="list-style-type: none"> ● Diaphragmatic breathing exercises ● Progressive walking program, either by increased duration or distance walked each session ● Strengthening exercises (listed above) ● Encouragement to stand for all | <p>3 <i>Fatigue or nausea during or after cancer treatment</i></p> <ul style="list-style-type: none"> ● Relaxation training, including deep breathing exercises ● Walking program ● Active range of motion exercises ● Aquatic exercise (the supportive environment of the water may increase patient tolerance for activities) ● Education regarding energy conservation techniques | <p>6 <i>Adhesive capsulitis (frozen shoulder) or other orthopedic problems experienced post-operatively or as a result of cancer treatment</i></p> <ul style="list-style-type: none"> ● Ultrasound for deep heat to relax tissues and facilitate stretching (often combined with the use of an anti-inflammatory medication such as hydrocortisone to further reduce pain) ● Manual stretching of the glenohumeral (or other affected) joint to stretch the joint capsule ● Passive range of motion and, often, aggressive stretching ● Active movement and strengthening ● Education in proper posture to facilitate optimal movement |
| <p>4 <i>Post-radiation tissue fibrosis</i></p> <ul style="list-style-type: none"> ● Massage to decrease tightness ● Stretching exercises ● Myofascial release techniques ● Spray and stretch with vapor-coolant spray to decrease tissue restrictions ● Education on self-massage techniques | <p>5 <i>Lymphedema of an extremity after a lymph node dissection or radiation-induced fibrosis</i></p> <ul style="list-style-type: none"> ● Specialized massage techniques to facilitate lymph flow/drainage ● Compression wrapping of extremity with a specific type of bandage ● Sequential compression pump ● Active range of motion exercises | <p>7 <i>Trismus (loss of jaw movement) due to progressive post-radiation fibrosis</i></p> <ul style="list-style-type: none"> ● Heat or ultrasound to facilitate stretching ● Massage to jaw and neck musculature ● Manual stretching techniques ● Use of a passive stretching device on a regular basis |

weight lifting activities, or combinations of walking and weight lifting.^{4,6} Most patients were able to achieve significant results in six to eight weeks.

An early step in the cancer rehabilitation program development process was staff education. Staff members from both the rehabilitation and the radiation oncology departments attended a continuing education course entitled, "Advanced Rehabilitation of the Cancer Patient," taught through North American Seminars, Inc. The course outlined the benefits of exercise for the oncology patient and provided safe patient activity guidelines based on various test or laboratory results. The medical oncology department was involved in all the planning steps of the program but did not send a participant to this course. At our facility, medical and radiation oncology work closely under one director.

The next task was to educate the entire staff, including the medical and radiation oncology staff, physicians, and the rehabilitation staff. In-service and hands-on cross-training sessions included education on:

- Types of cancer
- Treatment methods and their side effects
- Relevant laboratory tests and results
- Physiological and psychological effects of cancer and its treatment
- Documentation of medical necessity and functional goals
- Benefits of exercise and therapeutic goals for patients with cancer
- The rehabilitation assessment and treatment process
- Use of rehabilitation screening tools to identify appropriate patients.

Screening and Evaluation

Developing a good screening tool was crucial to being able to identify appropriate patients for rehabilitation. Our staff developed a patient questionnaire that rates a patient's functional limitation on a five-point scale in these 10 areas:

- Fatigue
- Nausea
- Pain
- Difficulty with self-care (i.e., bathing, dressing, hygiene)
- Difficulty with mobility (i.e., getting up from bed or chair, standing, walking)
- Difficulty with community management (i.e., driving, shopping, endurance walking)
- Difficulty with household management (i.e., cooking, cleaning, laundry, yard work)
- Difficulty with work activities (i.e., job or volunteer activities)
- Difficulty with quiet recreation (i.e., hobbies, crafts, reading)
- Difficulty with active recreation (i.e., sports, travel, outings).

Higher scores reflect greater limitations and a need for therapy. We set a threshold score of 35 points for a rehabilitation referral, although this number is not a requirement. Many patients with lower scores have been referred because they were experiencing a fast decline in functioning or were interested in preventing limitations.

Rapid functional decline can be detected earlier in patients who undergo repeat screening during oncology treatment.

A physician referral for rehabilitation should include a Karnofsky Scale score, which is designed to measure a patient's ability to carry out ADLs. The referral should also include clinical laboratory results, including a hematocrit/hemoglobin, a platelet count, a granulocyte count, sodium and potassium levels, the percentage of bone involved with metastatic disease, the amount of osteoporosis, and any abnormal chest X-rays, ECGs, and pulmonary function test results.⁷ This information helps to determine what level of exercise or activity is safe for each patient to perform.

To optimize reimbursement for rehabilitation services, referrals should include a functional diagnosis in addition to the patient's oncology diagnosis. Because reimbursement guidelines are based on medical necessity, physician education on this topic is important. Any patient with functional limitations referred to therapy by a physician should be eligible for reimbursement if documentation supports the limitations and a reasonable expectation for improvement with treatment.

Insurance reimbursement for program services is usually very good, since most insurance carriers cover outpatient therapy services. We complete all coding according to a patient's functional diagnosis rather than the oncology diagnosis to further facilitate the best possible payment. This diagnosis is based on whatever functional activities are limited and what is creating the limitation. Since every patient will have different limitations, providing an all-inclusive list is impossible. The following examples are functional diagnoses that can be addressed by rehabilitation and are most likely to be considered for reimbursement:

- Impaired joint mobility, muscle performance, and range of motion, includes strength, power, and endurance
- Impaired gait, locomotion, and balance with increased risk of falls
- Impaired aerobic capacity and endurance to complete ADLs
- General weakness restricting ADLs
- Difficulty or inability to perform safe transfers
- Gait instability or disturbance
- Difficulty or inability to complete ADLs.

Those with assigned ICD-9-CM codes are:

Fatigue-limiting ADLs	780.7
Nausea-limiting ADLs	787.0
Generalized pain limiting function	780.9
Weakness limiting ADLs	780.7
Muscular wasting, disuse atrophy	728.2
Difficulty walking	719.7
Lymphedema	457.1
Breast pain	611.71
Adhesive capsulitis	726.0

Ongoing Interdepartmental Involvement

A partnership among radiation oncology, medical oncology, and rehabilitation was important to the program's success. A staff liaison from the rehabilitation department visits oncology patients, staff, and physicians on a

Up Close and Personal

After 59-year-old John finished treatment for oral cancer, he had a limited ability to take bites of food, chew, and swallow. He was so embarrassed by these challenges that he chose to isolate himself from others to avoid humiliation. Through exercise, soft tissue mobilization, and massage, he reported improved function and satisfaction. More importantly, he felt comfortable sharing meals with his family again. His performance and satisfaction scores on the COPM increased from 38 to 78 points on a scale of 100 over a span of seven treatments—a 40 percent functional improvement.

Mary, 74, had recently finished both chemotherapy and radiation therapy for esophageal cancer. She was limited in her ability to perform prolonged walking, household chores, and caring for her grandchildren. She also experienced general weakness throughout her body. Her rehabilitation treatment consisted primarily of endurance and strengthening exercises, as well as safety education. Upon completing the cancer rehabilitation program, she could walk twice as far and exercise twice as much as she could when she started and had regained all her prior strength. Her performance and satisfaction

scores on the COPM increased from 56 to 93 points—a 37 percent functional gain.

She now performs everyday tasks and household chores and has been able to return to her top priority of spending time with her six grandchildren.

Anita, 55, who was diagnosed with breast cancer in 1993, thought she was cured after undergoing a mastectomy and receiv-

ing chemotherapy treatment. In November 2000, however, she was diagnosed with ovarian cancer.

After undergoing a hysterectomy and receiving chemotherapy treatment at St. John's Health System, Anita developed the most common symptom of cancer patients—excessive fatigue.

After an assessment of her condition in June 2001, her oncologist at St. John's recommended that she participate in the hospital's Cancer Rehabilitation Program to build up her physical strength. With the recommendation from her oncologist, and approval from her insurance carrier, she joined the program.

Anita initially could walk only 150 feet before experiencing shortness of breath and increased nausea/vomiting. She also had significant weakness in her legs and impaired balance. Anita's priority functional limitations included walking, cooking, cleaning, driving, and general mobility.

Anita participated in the rehabilitation program twice a week. Her initial tolerance was for only 30 minutes of exercise, but her stamina improved to allow approximately an hour of activity. The physical therapist worked with her to build up strength and endurance through stationary bike riding, strengthening exercises on a mat, treadmill walking, and light weightlifting on exercise equipment. Balance exercises helped Anita increase her safety when she performed daily tasks.

Records were kept of Anita's progress throughout treatment. After the initial evaluation, reports were sent to her oncologist for physician approval of the treatment plan, as well as for any follow-up physician appointments during treatment and at completion of the program.

The initial plan for Anita was for four to six weeks of treatment. At four weeks, she continued to show limitations in strength and endurance, so she continued in the program for two more weeks at the advice of her physician and PT. Her insurer will probably pay the \$1,300 for her care.

Anita has reached her goals of being able to go with her husband to the grocery store and visit family and friends "without feeling breathy," but she still has to sit down and rest periodically.

Her initial total COPM Score was 50 and final total score was 98, which represents a functional improvement of 48 points (see Table 2).

Anita may benefit from further therapy services since she is currently undergoing another round of chemotherapy. Patients usually do not need to return to the program and many continue their exercises independently long after formal rehabilitation is completed. 🗣️



Anita's physical therapist worked with her to build up strength and endurance.

Table 2: Anita's COPM Scores

Patient's Priority Functional Limitations	Performance Rating (Scale of 1 to 10)		Satisfaction Rating (Scale of 1 to 10)	
	Pre-test	Post-test	Pre-test	Post-test
General mobility	5	9	4	10
Walking	4	10	5	10
Cooking	4	10	4	10
Cleaning	4	9	4	10
Driving	8	10	8	10

regular basis, which is helpful for oncology patients who have rehabilitation needs that are not significant enough to warrant a referral for the comprehensive program. Patients who do not need extensive rehabilitation services may still benefit from education on how they can help themselves through home exercise. Education about walking programs, general aerobic activity, safe use of adaptive equipment, and home exercise has become a regular part of these contacts with patients.

Since the rehabilitation liaison representative is also a member of our hospital's Cancer Committee, open communication is fostered among departments. The rehabilitation department presents reports at the committee's quarterly meetings, which outline the successes and benefits of the program for oncology patients.

Interventions and Outcomes

Interventions provided by physical, occupational, and speech therapists benefit oncology patients by relieving or reducing their nausea, fatigue, pain, functional limitations, lack of conditioning, and disabilities. The main focus of physical, occupational, and speech therapy is to identify functional limitations, to determine (with the patient) limitations that are the most important, and to develop plans on how to impact these limitations in a positive manner. Every patient who is referred for rehabilitation has distinctive needs and goals, which the staff should identify and use to individualize each treatment plan (See Table 1).

The Saint John's staff uses the Canadian Occupational Performance Measure (COPM[®]) as its outcome tool. The COPM (<http://www.caot.ca/copm>) is an individualized, patient-centered instrument designed for use by occupational therapists to detect changes in patients' perceptions of their occupational performance over time. The COPM is a standardized instrument designed as an outcome measure, with a semi-structured interview format and a structured scoring method.

In the COPM, the patient rates the importance of each functional limitation. The five top items are rated for performance and patient satisfaction on a scale of 1 to 10, resulting in a base score out of a possible 100 points. The COPM is extremely useful in determining patient priorities and goals and developing individualized treatment plans. Patients are very enthusiastic about being included in the planning and the obvious effort to address their priorities.

The patient's goals and priorities are coupled with the objective findings to develop an overall plan. Corrective treatment is classified as preventive, palliative, supportive (when significant improvements are anticipated), or, most often, restorative (when the patient is expected to return to a prior level of functioning).

Saint John's ability to individualize treatment plans to meet each patient's needs allows patients to achieve meaningful results in less than six to eight weeks.

All patients undergoing rehabilitation at St. John's rate their functional performance upon entering and upon completing the program. Since the result is based on a 100-point scale, results are easy to interpret. To date, a 35-percent average gain has been reported for all patients completing the program. This figure represents

a 35 percent improvement in both functional performance and patient satisfaction in the areas identified as most important by each patient. The average number of visits for patients who complete the program is 7.2 over a period of four weeks.

Challenges Facing the Program

Creating and sustaining interest in the rehabilitation program—particularly among the oncology staff—has been difficult. Since the program is new, keeping it on

Every patient...referred for rehabilitation
has distinctive *needs and goals*...

the minds of the oncology staff is challenging, despite its successes. Interdepartmental communication and interaction remain key to the program's success. We keep the lines of communication open by sending the rehabilitation staff on regular visits to oncology areas and conducting meetings as needed. No separate funding or budget for this program exists, so the time must be blocked from the therapist's regularly scheduled working hours. The small amount of time visits take each month appears to be more than compensated for in revenues created from referrals to the program, so no specific funding is being sought at this time.

Patient resistance to the cancer rehabilitation program is another obstacle. Many patients say they are too fatigued and overwhelmed to add one more activity, or that their pain is too severe for them to participate in the program. Discussions with patients about the benefits and the symptom control the program offers often encourage patients to participate.

We have also experienced lower referral numbers than we had anticipated. We have had 47 referrals for cancer-related services over the past 15 months, and this number includes referrals for specific secondary diagnoses such as lymphedema or tissue fibrosis. Only 16 referrals for the more comprehensive program discussed in this article have been made. About 80 percent of the referrals come from within the Saint John's Health System, and 20 percent come from the community. To increase program participation, we continue to hold education sessions with the oncology nursing staff on how to "market" the program to potential patients. We also hold ongoing education sessions on identifying patients that would most likely benefit from the rehabilitation program.

Another important part of increasing the number of referrals has been disseminating information about the program directly to the public through newspaper articles, radio talk programs, brochures, and bulletin boards. Interestingly, patients are empowered by and respond to these announcements.

The last significant obstacle we have encountered is the reluctance of some physicians to refer patients with a terminal diagnosis. Still, the positive patient and family

What Other Cancer Centers Are Doing

Oncology Issues surveyed a number of cancer centers around the country to see how they provide rehabilitation services for their cancer patients.

◆ *Bethesda Memorial Hospital* (Boyton Beach, Fla.) developed a program called Cancer Rebound Rehabilitation, as well as a rehabilitation program specifically for breast cancer patients. The issues and concerns of each cancer patient are unique. To help patients cope with numerous personal challenges, Cancer Rebound's licensed therapists provide assistance in five major categories: 1) chronic fatigue, 2) generalized weakness, 3) neurological symptoms, 4) pathological fractures, and 5) peripheral neuropathology.

◆ *M.D. Anderson Cancer Center's* (Houston, Tex.) Palliative Care and Rehabilitation Program is one of the largest cancer rehabilitation programs in the U.S. Two teams—an inpatient mobile team and an outpatient team that works at the outpatient care center—provide cancer rehabilitation services to M.D. Anderson patients, as well as to patients from other facilities. M.D. Anderson has developed a multidisciplinary team that includes medical oncologists, anesthesiologists, and physical, occupational, and speech therapists who assess and manage

severe cancer-related symptoms.

The research programs at M.D. Anderson's Palliative Care and Rehabilitation Program are continually identifying new ways of assessing and managing severe physical or psychosocial symptoms in advanced and terminal cancer patients. M.D. Anderson also offers continuing education opportunities for cancer specialists, community health care workers, and medical students and residents who want to learn the latest in palliative cancer care, end-of-life care, and cancer rehabilitation.

◆ The Milton J. Dance Head and Neck Rehabilitation Center at the *Greater Baltimore Medical Center* (Baltimore, Md.) provides comprehensive rehabilitation services for patients receiving treatment for cancers of the head and neck. The program's integrated approach combines the disciplines of surgery, oncology, dentistry, speech-language pathology, nursing, social work, and physical, cognitive, and occupational therapy. The center uses sophisticated voice and dysphagia (swallowing) programs and state-of-the-art equipment including videostroboscopy, videofluoroscopy, fiber optic endoscopy, and a swallowing workstation to help patients with speech, language, voice, cognitive, communication, or swallowing disorders as a result of cancer and cancer treatment.

While many cancer centers did not offer a stand-alone rehabilitation program, they incorporated rehabilitation services in other program areas. A number of hospitals offered rehabilitative services under their pain management programs. For example, in Los-Angeles, Calif., *Cedars-Sinai Comprehensive Cancer Center's* Cancer Pain Management Service (CPMS) works with the patient's primary oncologist to develop an individualized pain and symptom management plan. The patient and family members actively participate in creating the treatment plan, which incorporates traditional medication and intervention strategies with behavioral and supportive techniques developed by the team's licensed psychiatrists, psychologists, social workers, art therapists, and oncology pain nurses. While not regular members of the team, physical and occupational therapists, specialists in anesthesia pain management and head/neck pain management, and neurosurgeons are readily available for consultation.

Because patients are referred to palliative care to relieve many of the same functional limitations (i.e., pain, nausea, fatigue, weakness, and anxiety) as patients referred for rehabilitative services, many cancer centers offered rehabilitation services in conjunction with palliative care. 📌

feedback about improvements in functional independence and quality of life are a testament to how the rehabilitation program has benefited even patients with terminal cancer.

We have not conducted any formal studies on the long-term benefits of the program, but have done follow-up patient phone surveys. Patients have been very satisfied with the program and have had continued success when performing the recommended exercises at home.

Saint John's experiences and outcomes demonstrate that a well-run rehabilitation program can make a significant contribution to quality survivorship and give patients a number of functional and quality-of-life benefits, as well as an opportunity to regain control over their lives. 📌

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