Introduction

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DOI: 10.1891/9780826121646.0001

The History of Cancer Rehabilitation

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Soon after I accepted the editors' flattering invitation to write this chapter on the history of cancer rehabilitation for the first edition of this worthwhile text, I ventured into the voluminous library of the Texas Medical Center. My aim was to start research on the early years of cancer rehabilitation. Using the key words of "rehabilitation, cancer, and oncology" in a computer search, I was able to find only one volume that was published prior to 1980. This tome, Cancer Rehabilitation: An Introduction for Physiotherapists and the Allied Professions, was written by Patricia A. Downie, FCST, and published in London in 1978 (1). A meticulous and informative work, this book seems to have been written by and for physiotherapists (physical therapists); I was later loaned a book, Rehabilitation of the Cancer Patient (1972), courtesy of Dr. Ky Shin.

In an attempt to find resources with more of a physician orientation, I proceeded to a section on physical medicine and rehabilitation. I began my search by perusing the first (1965) and second (1971) editions of the venerable Handbook of Physical Medicine and Rehabilitation by Krusen et al. (2). To my dismay, and some surprise, neither of these two first editions had a chapter, or even a paragraph, on "cancer rehabilitation." In both volumes, the word cancer was only mentioned in regard to the skin cancer being caused by light, in particular, ultraviolet therapy. The word tumor appeared when discussing intramedullary spinal cord tumors in a chapter on electromyography. Malignancy and oncology were not mentioned at all. The book Physical Medicine and Rehabilitation for the Clinician, edited by Frank H. Krusen and published in 1951, similarly made no mention of cancer rehabilitation (3). The first, second, and third editions of Proceedings of the International Congress of Physical Medicine similarly made no mention of cancer rehabilitation. Drs. Bierman and Licht edited multiple volumes of Physical Medicine in General Practice, where again no mention was made of cancer rehabilitation. But in one chapter, on surgical diathermy, a mention was made of electrocoagulation of malignant tissue. These volumes span the 1940s and early 1950s (4). With my search essentially revealing no information of use, I came to understand very quickly the meaning of the word obscure (obscure has many definitions, which include "not clear or distinct," "faint or undefined," "in an inconspicuous position," "not well known," etc.).

Finally, further desperate searching yielded "pearls." I came upon the volumes edited and/or written by a pioneer

in physical medicine and rehabilitation, Dr. Howard Rusk. The volume, *New Hope for the Handicapped*, which he coedited with Dr. Taylor and which had multiple editions published in the late 1940s, actually mentioned cancer as a "special rehabilitation" problem within a chapter on rehabilitation of surgical patients (5). His first volume of the seminal work, Rehabilitation Medicine, had a full chapter on cancer rehabilitation in the initial 1958 edition, as well as the second and the third editions. By the fourth edition in 1977, Dr. Rusk had literally tripled the size of the chapter to be quite inclusive (6). His wonderful 1972 volume, A World to Care For, not only reviewed specific medical issues and problems of the cancer patient, but also detailed specific government legislation, speculated on why there was very little cancer rehabilitation being performed in the United States, and, finally, shared with the readers his initial efforts in setting up a cancer rehabilitation program in the 1960s (7).

Armed with this information from Dr. Rusk and with added inspiration, I finally had the emotional and tangible wherewithal to commence my journey into the beginnings of cancer rehabilitation.

LEGISLATION

In the mid-1960s, President Lyndon Johnson recommended a special presidential commission to investigate and recommend ways to reduce the incidence of heart disease, cancer, and stroke, the grave killer diseases that affected millions of Americans each year (7–9). Dr. Michael DeBakey, the renowned vascular surgeon, was appointed chair of this commission, which included 25 specialists in various fields. The main purpose of the group was to work out a master plan to attack these three serious diseases. Dr. Rusk was a member of this group and effectively argued for rehabilitation, both philosophically and as a process.

Ultimately, Dr. Rusk was authorized by Dr. DeBakey to create and chair a subcommittee on rehabilitation needs and programs. Joining Dr. Rusk on this subcommittee were several rehabilitation specialists, including William Spencer, Henry Betts, William Erdman, Arthur Abramson, Paul Elwood, and others. The commission report was the basis for the enactment and passage of Public Law 98–239, the Heart, Cancer, and Stroke Act. The program was enacted in 1965 and established regional medical programs

for the diagnosis, treatment, and rehabilitation of people with these three diseases.

It was determined that this mission could best be accomplished through regionalization in cooperative arrangements among a region's medical resources. It was thought that such an arrangement would enable the medical profession and its institutions to make available to all citizens the latest advances in diagnosis and treatment of these diseases. Because of the voluntary nature of American medical institutions, the legislation allowed for a flexible framework in the implementation of a regional approach. Programs were also to do research and to train professionals to deal with the diseases. Programs were to be centered in medical schools and teaching hospitals, and rehabilitation was to be a focus of all programs (9).

According to Klieger, the intent of the act toward accomplishment of this goal was to build upon and encourage the following:

- Utilization of existing institutions and manpower resources
- 2. Participation of practicing physicians
- 3. Regional initiative, planning, and implementation under conditions that encourage innovative approaches and programs
- 4. Cooperation among elements of the health resources in a region
- 5. Effective linkages between research advances and improved patient care
- 6. A continuing process of education throughout the career of a physician in bringing the benefits of new knowledge to the patient (9)

The regional medical programs were to serve as instruments of synthesis within each region to reinforce the various groups seeking the latest advances in the diagnosis and treatment of these diseases. The importance of rehabilitation in the regional medical programs was outlined by the subcommittee under the chairmanship of Dr. Rusk. The subcommittee emphasized the necessity of rehabilitation as an integral part of the total rehabilitation of individuals with these diseases. It was observed, however, that despite efforts by public, professional, and voluntary agencies, the potential of rehabilitation, its concepts, and its methods were not well understood. The report pointed out that physicians must realize that rehabilitation existed as a service program for them and their patients afflicted with cancer; that programs must be designed to help the physician meet the retraining needs of patients who have been disabled as the result of surgery or radiotherapy for cancer; that comprehensive regional programs must be included as a service in every stroke center or station to accommodate patients with physical disabilities and those with communication disabilities resulting from aphasia; and that continuing education for physicians is an important contribution to the more effective utilization of rehabilitation concepts and methods in services for patients with heart disease, cancer, and stroke (9). Theoretically, this act began the special programs in stroke, cancer, and cardiac rehabilitation and lasted into the 1970s.

Other important legislations enacted by Congress in the 1960s and affecting rehabilitation medicine were the amendments to the Rehabilitation Act signed into law by President Johnson in late 1965. The act created a new facility construction program and dramatically expanded the funding for federal, state, and vocational rehabilitation services by raising the federal share of these services to 75% of total funding (10). Before Medicare, the Rehabilitation Act was the only federal healthcare funding for rehabilitation medicine to adult civilians who were not veterans. Again, Dr. Howard Rusk was the champion of the legislation. However, it seems that little was accomplished in the cancer rehabilitation area. Harvey notes that in 1971 only 1,000 of 260,000 clients served by the vocational rehabilitation program were cancer patients (11).

In 1971, the National Cancer Act was passed, and funds became more readily available for the development of training, demonstration, and research projects in rehabilitation and were administered through the Division of Cancer Control and Rehabilitation, National Cancer Institute (NCI) of the National Institutes of Health (NIH) (11,12). NCI contracts and grants were to be awarded to address a variety of topics, such as development of model rehabilitation programs, hospice care, pain-management programs, and interventions to reduce psychosocial morbidity. According to Mayer, these contracts and grants did not produce the desired effect. Interest and support waned and shifted to more cure-oriented areas (12). Grabois adds that "... the passing of this act had little impact on the rehabilitation of patients with cancer. These efforts failed due to a lack of a specific implementation plan, a lack of trained personnel, and failure to educate referring health care professionals" (13).

In 1973, legislation was promulgated that indirectly protected cancer patients from discrimination. This was the National Rehabilitation Act of 1973 and included a number of civil rights protections for people with "handicaps." Section 504 of this title prohibited discrimination against people with "handicaps," now defined as disabilities, by any federal department or agency that entered into a contract in excess of \$2,500 (14,15). This included almost all educational institutions, hospitals, and most public bodies. In such institutions, affirmative action was mandated to be taken to employ, advance, or preserve the benefits of any "qualified handicapped" individuals. A violation could be filed as a grievance with the Department of Labor. This act in essence was a precursor of the Americans with Disabilities Act, which extended the prohibitions against job discrimination to all employers.

PROGRAMS AND PEOPLE

The early history of cancer rehabilitation certainly would not be complete without a review of some of the pioneer rehabilitation programs. Although the political legislation of the 1960s and 1970s was lofty and admirable, seemingly very little tangible benefit accrued to cancer patients and indeed most cancer rehabilitation programs. Nonetheless, two early programs are worthy of review: those at the University of Texas MD Anderson Cancer Center (MDACC) and a cooperative program started by Drs. Rusk and Dietz in New York City (16). It would be of benefit in understanding cancer rehabilitation history to now review those programs.

From approximately 1960 until 1973, the MDACC at the burgeoning Texas Medical Center employed a physiatrist

from a rehabilitation consultation service that had electrodiagnostic capabilities. In addition, physical and occupational therapy departments were in existence. The program was not closely aligned with any particular teaching program, as Dr. Martin Grabois has pointed out. For 5 years following 1973, not only was a physiatrist present at the cancer center; there were also rotating residents. This rotation apparently was given favorable reviews by the rotating residents. Unfortunately, for the following decade, this program experienced quite a bit of negative turbulence. There was no longer a physiatrist, and the residency rotation ceased to exist. The Occupational Therapy Department was also discontinued and a nonphysiatrist headed the program. Finally, in 1989, the cancer center approached the Department of Physical Medicine and Rehabilitation at Baylor College of Medicine to develop a meaningful cancer rehabilitation program. According to Grabois, initial attempts at forming such a program were unsuccessful for a variety of reasons, which relate to the physiatrists employed, the lack of follow-through in educating referring physicians, and insufficient clinical and office space. In the early to mid-1990s, further efforts were made to rejuvenate the program. The MDACC joined with the Department of Physical Medicine and Rehabilitation at Baylor College of Medicine in developing a program that has become quite significant (13). More recently, the graduate resident affiliation has become more closely affiliated with the University of Texas at Houston (UTH) Medical School and senior level residents from that institution now may rotate through the cancer rehabilitation service.

Dr. Ky Shin, current head of the section, reports that there are now eight full-time physiatrists with two midlevel advanced practice nurses on staff. Yearly, two cancer rehabilitation fellowships are offered. These specialists in physical medicine and rehabilitation exclusively practice cancer rehabilitation and are in the Section of Physical Medicine and Rehabilitation in the Department of Palliative Rehabilitation and Integrative Medicine. In addition to an inpatient rehabilitation unit (14–16 beds at any time) and an inpatient consultation service, there is a large outpatient program. The emphasis for admission to the MDACC rehabilitation unit has been to take patients with multiple impairments and more comorbidities or diseases. Thus, despite a variety of past tribulations and uncertainty, the cancer rehabilitation program at MDACC is now thriving.

In New York City, the seminal cancer rehabilitation program was started in the mid-1960s. Dr. Howard Rusk in A World to Care For details a patient with bladder cancer who required a hemicorporectomy at New York City's Memorial Hospital (7). After being transferred to the Institute of Rehabilitation Medicine, the patient ultimately was able to return home to his family. This success provided Dr. Rusk with encouragement in the rehabilitation of cancer patients. He partnered with Memorial Hospital's Dr. Herbert Dietz, a surgeon from upstate New York who came to New York City and spent 2 years studying rehabilitation, especially of cancer patients. Thus, a joint undertaking with Memorial Hospital and the Institute of Rehabilitation Medicine took place, and a cancer rehabilitation program developed in New York City (7). After Dr. Dietz's retirement, there were difficulties within the program. Throughout the 1980s and 1990s, there were often periods with no physiatrist and a lack of a very organized program.

Dr. Michael Dean Stubblefield became the sole physiatrist at Memorial Sloan Kettering Cancer Center (MSKCC) in 2001. There had not been a physiatrist or an outpatient program for at least a year and there were only about 10 therapists, all doing inpatient work. During his nearly 14 years at MSKCC, Dr. Stubblefield became Chief of Service and helped grow the staff to five physiatrists, approximately 100 therapists, and nearly 20 support staff. A \$17 million gift from one of Dr. Stubblefield's patients facilitated the establishment of a 22,000- square-foot outpatient cancer rehabilitation center. A major factor in the success of the MSKCC program was the shift in focus from a traditional emphasis on the management of lymphedema to evaluation of management of neuromuscular, musculoskeletal, pain, and functional complications of cancer and cancer treatment. Dr. Stubblefield pioneered the use of botulinum toxin and other injections in the cancer setting to relieve pain and improve function. The MSKCC rehabilitation service has become involved in a number of research trials, including collaboration with other services throughout the center. In recent years, the rehabilitation service has offered inpatient consults and a heavily emphasized outpatient program.

A review of the two historic programs detailed previously highlights the difficulties and cycles that the programs in cancer rehabilitation have endured over the past five decades. Nonetheless, both of these programs have survived and are now successful.

Surveys of cancer rehabilitation programs have been sparse. The excellent survey by Harvey and associates was done over 30 years ago (11). Anecdotal comments from professionals that I have interviewed are unanimous in emphasizing that there are only a very few centers in the United States and Canada where comprehensive rehabilitation programs exist and these are usually at larger cancer hospitals/centers. It is not known exactly how and by what means the majority of cancer patients elsewhere are treated and what attention is given to their rehabilitation needs. Logically, the rehabilitation problems of cancer patients could be addressed by their hospitals' or communities' general rehabilitation program(s).

On a professional level, more than three decades ago the Cancer Rehabilitation Special Interest Group (SIG) was formed within the American Academy of Physical Medicine and Rehabilitation (AAPMR). It continued until the dissolution of the SIG structure occurred in 2008. Cancer rehabilitation is currently under the umbrella of the General Medical Rehabilitation Council. In addition, the AAPMR is now a member of the Congress on Cancer, the largest accrediting group under the "Cancer Umbrella." At the 2016 AAPMR Annual Assembly, diligent specialists in cancer rehabilitation held a Cancer Rehabilitation Summit with over 100 attendees. A very successful cancer rehabilitation precourse was held at the 2017 meeting.

NEED

Historically, the recognition that cancer patients had many rehabilitation needs was often clouded by common "perceptions" about the hopelessness of their condition and their acute medical needs. As early as 1969, the wonderful pioneer Mary Switzer, in a lecture given in 1970 in Houston, Texas, reported that of 260,000 people rehabilitated through

the Public Vocational Rehabilitation Program in 1969, only about 1,000 were the victims of cancer (17). Fortunately, since that time, quite a few excellent papers have shed light on the rehabilitation needs and problems of cancer patients.

In 1978, Lehman and his coworkers provided an extremely informative and certainly convincing review of the needs of cancer patients. Surveying more than 800 patients from several hospitals, they identified many needs (Figure 1.1), including those involving activities of daily living (ADL), ambulation, family support, psychological distress, pain, and weakness. A mode of care was then organized based on the findings of the needs assessment. Ultimately, after the formation of a clinical oncology team, the number of referrals and therapy treatments greatly increased (18).

DePompolo reported the experience of the cancer rehabilitation program at the Mayo Clinic. Again, his findings certainly buoy the concept that cancer patients have many needs for rehabilitation. He outlined many of these, which included psychological issues of emotional support and assistance, pain and impairments in activities of daily living, and mobility (19). Sabers and coworkers, also from the Mayo Clinic, reviewed the rehabilitation needs of 189 patients referred to the Cancer Adaptation Team over an 8-month period. Pain was identified as a significant need

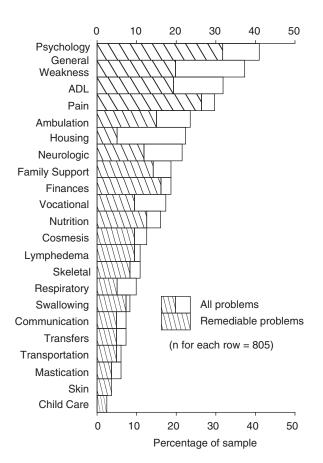


FIGURE 1.1 Percentage of patients with various rehabilitation issues in Lehman's seminal work.

ADL, activities of daily living.

Source: From Lehmann JF, DeLisa JA, Warren CG, et al. Cancer rehabilitation: assessment of need, development, and evaluation of a model of care. *Arch Phys Med Rehabil*. 1978;59:410–419.

in almost three-quarters of the patients. Other findings revealed that almost the same number had difficulty rising from a chair and more than three-quarters had problems getting on and off a toilet, getting in and out of a bathtub, walking, and climbing stairs (20).

Whelan reviewed the symptoms and problems of cancer patients, which they themselves identified. Paramount among these included issues concerning sleep, pain, fatigue, and worry. These cancer patients revealed that they needed more education, more help with activities of daily living, and help with social support (21). Winningham, in many scholarly works, has continued to prove that fatigue and pain are major concerns of cancer patients (22,23).

Van Harten in the Netherlands performed a comprehensive review of the literature regarding the needs of cancer patients. A wide array of psychological impairments and emotional issues was identified as well. In his own survey of 147 cancer patients, more than one-quarter felt the need for professional care and, of these, 17% indicated problems in more than one area. Their problems included not only physical function but also psychological and cognitive functions (24). Stafford and Cyr, in a review of 9,745 elderly, community-based Medicare patients sampled in the 1991 Medicare Current Beneficiary Survey, found that more than 1,600 had been reported as having a diagnosis of a malignancy that was not skin cancer. These individuals reported poor health, more limitations with activities of daily living, and greater healthcare utilization. Some of their common concerns included gait difficulty and difficulty getting out of a chair, while many had trouble completing housework and shopping (25).

Clearly, the needs of cancer patients relating to rehabilitation are multifold and complex. It is of interest that over the past 20 years, in particular, the reports of cancer rehabilitation therapy have broadened in scope. The early, pre-1980 descriptions were clearly associated with common anatomical sites of malignancy and the more obvious side effects of the tumor and the treatment. Recently documented successful efforts have gone beyond just a single anatomical site and have focused on more holistic issues affecting the cancer patient, such as fatigue, pains, and a lack of social support.

Asher, as well as Kroenke in 2012, listed the common symptoms reported by cancer patients (26). These included:

- Fatigue (42%–92%)
- Insomnia (41%–54%)
- Cognitive dysfunction (17%–34%)
- Depression (15%–30%)
- Anorexia (32%)
- Pain (36%)
- Constipation (27%)
- Dyspnea (26%)
- Nausea (21%)
- Dry mouth (42%)
- Numbness/Tingling (29%)
- Dizziness (20%)

However, under-referrals remain a major stumbling block for the comprehensive care of cancer patients. A review of recent literature highlights this dilemma. Movsas et al. in 2003 reviewed the functional needs of patients on an inpatient oncology unit and found that only 18% of patients received a physiatry consult (27). Cheville in 2008 documented the impairments of 163 outpatients with metastatic breast cancer and found a total of 530 impairments. Of these patients, only 30% received any functional treatment and/or assistance (28). Interestingly, the same author in 2017 found that over 30% of late-stage cancer patients expressed an interest in rehabilitation services (29).

EFFICACY

Dr. J. Herbert Dietz, in the 1960s, first provided some evidence as to the efficacy and worth of cancer rehabilitation. He classified his patient rehabilitation goals as:

- Restoration
- Support
- Palliation

He described 1,237 inpatients seen during the initial three years of the Cooperative Rehabilitation Program at Memorial Hospital. His ultimate conclusion was that "80% of patients treated have shown measurable benefits appropriate to the goal set for them" (30).

Unfortunately, almost a quarter of a century elapsed until further convincing evidence became available. Some of the more significant reports are detailed. In 1991, O'Toole and Golden reviewed the progress and outcomes of patients with cancer in a freestanding rehabilitation hospital. The majority of the 70 subjects made dramatic improvements in mobility and bladder continence. Ninety days after discharge, many had maintained or improved their functional level (31).

The previously mentioned work of Sabers et al. reported on the efforts of a consultation-based inpatient rehabilitation team in the treatment of hospitalized cancer patients. Functional status of the patients at enrollment and discharge was evaluated with the Barthel Mobility Index and the Karnofsky Performance Status Scale (Table 1.1).

TABLE 1.1 Karnofsky Performance Status Scale

RATING (%)	DEFINITION
100	No evidence of disease
90	Normal activity with minor signs of disease
80	Normal activity with effort; signs of disease
70	Cannot do normal activity but cares for self
60	Requires occasional assistance
50	Requires considerable assistance; frequent medical care
40	Disabled, requires special care
30	Severely disabled; hospitalization may be indicated
20	Very sick; hospitalization necessary for supportive treatment
10	Moribund
0	Death

Significant gains were made in both indices by the 189 patients studied (20).

Yoshioka, in Japan, reviewed more than 300 terminally ill cancer patients in an inpatient hospice setting. A variety of therapeutic interventions were performed by therapists. The Barthel Mobility Index increased from 12.4 to 19.9 (p < .0001) in those with ADL deficits. The families of these patients almost unanimously were appreciative of the care and rehabilitation efforts (32).

Phillip et al. surveyed the functional outcome after rehabilitation efforts of 30 children, aged 3 and older, who were treated for primary brain tumors. Using the Wee-Functional Independence Measure (Wee-FIM) as a functional independence measure, their study clearly documented positive effects of an interdisciplinary rehabilitation program on these pediatric patients with residual disabilities (33).

Marciniak et al. at the Rehabilitation Institute of Chicago summarized the progress of 159 patients over a two-year period undergoing inpatient rehabilitation secondary to functional impairments from cancer or its treatment. All cancer subgroups made significant functional gains between admission and discharge. Also, neither the presence of metastatic disease nor the delivery of radiation treatment influenced the functional outcome (34).

Kirshblum and O'Dell, in 2001, further summarized the outcomes of three prior studies of patients with brain tumors receiving inpatient rehabilitation. Although the methodology of the studies varied, it could safely be concluded that these patients with brain tumors "undergoing inpatient rehabilitation appear to make functional gains in line with those seen in similar patients with traumatic brain injury or stroke" (35). Winningham, in many excellent recent works, has reviewed the evidence, possible etiologies, and theoretical models of fatigue in cancer patients. She then describes the usefulness and benefits of a variety of programs, including exercise and other effective rehabilitation interventions (22,23). Clearly, at present, the efficacy and worth of rehabilitation efforts are proven and undoubted.

Recent works have documented the very positive effects of exercise and other rehabilitation therapies on functional improvement, independence, a feeling of well-being, and fatigue problems in the cancer patient. The HELP trial documented increased survivorship in lymphoma patients undergoing exercise programs (36). Mustian et al. performed a large meta-analysis of the most commonly recommended treatments for cancer-related fatigue and found that exercise and psychological interventions were of great benefit and more efficacious than available pharmaceutical options (37).

CANCER REHABILITATION: FROM PAST TO PRESENT TO FUTURE

The American Cancer Society has estimated that up to 1.68 million Americans were newly diagnosed with cancer in 2017 with more than 15.5 million cancer survivors alive in the United States today (38). As our population ages, the incidence and prevalence of cancer will only increase. However, 5-year survival rates for all cancers have greatly increased over the past 40 years. As an example, the 5-year survival rate for breast cancer has gone over 90% while that of leukemia has increased from 34% to 63% (38). Certainly, the modern-day cancer patient has a longer life span and may very well be thought to have a chronic illness, not just an acute deadly malady.

Although critics may state, perhaps rightfully, that the progress made in rehabilitating cancer patients and developing cancer rehabilitation programs has been slow, the labors and persistence of our cancer rehabilitation pioneers have certainly yielded some positive fruits. Clearly, the cancer population needs, and should demand, the services of rehabilitation professionals. Supported by the convincing pioneer works of their predecessors, the modern-day cancer rehabilitation specialist is empowered by evidence, inspiration, and experience to march forward and provide the expertise and support for this deserving population.

KEY POINTS

- Over the past two decades, there has been a steady improvement in the survival statistics for nearly all cancers, due in large part to earlier detection and advances in surgery, radiation, and chemotherapy.
- Longer survival of patients with cancer has led to an increase in the chronic, long-term toxicities associated with chemotherapy.
- Anthracycline-induced cardiovascular complications can arise acutely (during administration), early (several days to months following administration), or years to decades following exposure.
- Bleomycin therapy can result in lifethreatening interstitial pulmonary fibrosis in up to 10% of patients.
- Cisplatin is used to treat testicular, ovarian, bladder, esophageal, and head and neck cancers, as well as non-small cell lung

- cancer, small cell lung cancer, non-Hodgkin lymphoma, and trophoblastic disease, and is commonly associated with peripheral neuropathy and ototoxicity.
- Lhermitte sign is a shocklike, nonpainful, sensation of paresthesias radiating from the back to the feet during neck flexion, which can develop in patients receiving cisplatin, and typically occurs after weeks or months of treatment.
- Taxane-induced motor and sensory neuropathies are cumulative and dose and schedule dependent.
- A peripheral neuropathy develops in approximately 75% of patients who receive prolonged thalidomide treatment.
- Almost any chemotherapeutic agent can result in postchemotherapy rheumatism, and this is a fairly common clinical phenomenon.

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