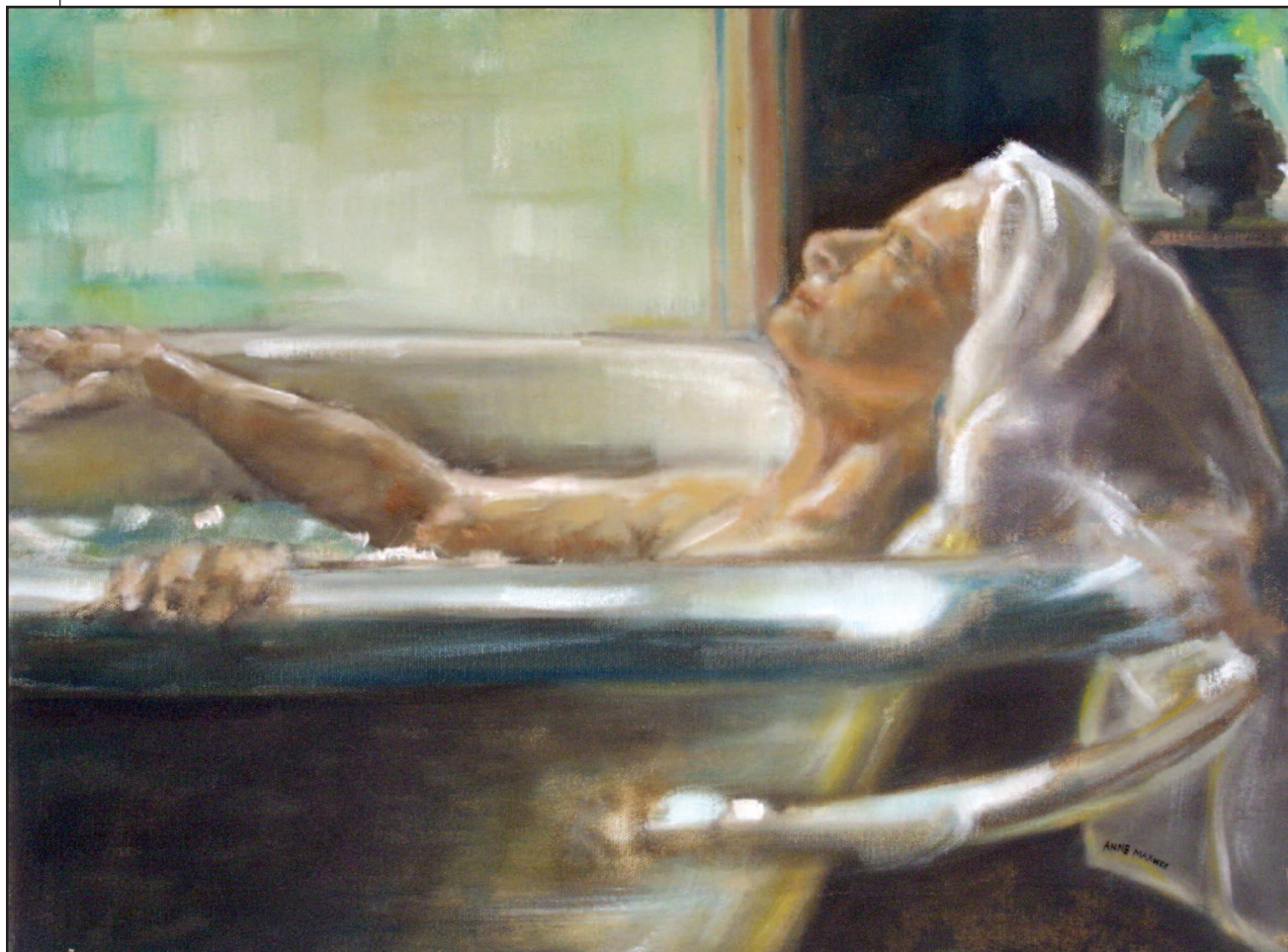


The Cancer Survivor's Prescription for Living

Nurses must take the lead in planning care for survivors.



Courtesy of Lilly Oncology on Canvas / Dr. Anne Maxwell

"The Long Soak" by Dr. Anne Maxwell of South Africa, won best oil by a health care provider in the 2006 Lilly Oncology on Canvas: Expressions of a Cancer Journey art competition. For more information about the contest, see "On the Cover," page 39.

Overview: Late effects or long-term sequelae of cancer and its treatment, or both, occur in nearly 75% of all survivors of cancer. What can nurses do to help survivors live well? And where do nurses fit into a multidisciplinary approach to cancer survivorship? The authors consider these questions and offer A Prescription for Living, which clinicians and patients can use in individualizing care for cancer survivors.

Cancer survivors number more than 10 million in the United States,¹ a direct result of advances in diagnosis and treatment.² But these successes have come at a cost: most people who survive cancer live long enough to develop significant sequelae. The definition of *cancer survivor* used here originated with the founding charter of the National Coalition for Cancer Survivorship (NCCS) in 1986: “From the moment of diagnosis and for the balance of life, an individual diagnosed with cancer is a survivor.”³ When someone has cancer, family members, friends, and caregivers are also affected and are sometimes considered survivors as well.^{3,4}

In 2005 the Institute of Medicine (IOM) released *From Cancer Patient to Cancer Survivor: Lost in Transition*.⁵ Of the report’s 10 recommendations, the one that has gotten the most attention from professional organizations and grassroots advocacy and survivor groups is the call for the creation of a survivorship care plan for any patient who completes initial treatment. We believe this is so not because it’s the most innovative recommendation, but rather because it’s the one most likely to be implemented and because it could fill a need that cancer survivors have long identified.^{6,7}

The nursing profession has a long history of seeing cancer treatment in the context of each patient’s values, strengths and limitations, and resources. And the IOM report suggests that “oncology nurses could play a key role” in developing and reviewing a survivorship care plan.⁵ But how might this be achieved?

In July 2005 a symposium was convened in Philadelphia to describe the challenges of surviving adult cancers and to identify the gaps in nursing approaches to these challenges. The State of the Science on Nursing Approaches to Managing Late and Long-Term Sequelae of Cancer and Cancer Treatment included clinicians, researchers, educators, administrators, representatives from the pharmaceutical industry, and cancer survivors. *AJN* published the proceedings as a supplement in March 2006 (www.nursingcenter.com/ajnancancersurvivors).

At a second symposium of “nursing stakeholders,” *Coming Together to Improve Care: Nursing Responds to the IOM Report on Cancer Survivorship*, in November 2006, three major goals for nursing’s response to the needs of cancer survivors were established:

- Build the capacity to educate nurses, caregivers, patients, and the public on survivorship issues through venues that include undergraduate and graduate nursing curricula and continuing professional education.
- In conjunction with patients and their families, develop an interdisciplinary, evidence-based wellness plan (A Prescription for Living) as part of a cancer survival care plan.
- Develop a multinational research agenda related to cancer survivorship, and incorporate the findings into policy and practice.

Pamela J. Haylock is a cancer care consultant and doctoral student at the University of Texas Medical Branch, Galveston, and a past president of the Oncology Nursing Society. Sandra A. Mitchell is an oncology NP at the National Cancer Institute and a predoctoral fellow at the National Institutes of Health, Bethesda, MD. Tricia Cox is director of oncology services at John Randolph Medical Center in Hopewell, VA. Susan Vogt Temple is a senior executive clinical educator at GlaxoSmithKline Oncology in Seale, AL. Carol P. Curtiss is a clinical nurse specialist, Curtiss Consulting in Greenfield, MA, and a past president of the Oncology Nursing Society. The authors acknowledge Nancy Houlihan, MA, RN, AOCN, for her assistance in developing the template. Contact author: Pamela J. Haylock, pjhaylock@indian-creek.net.

Haylock has been a paid consultant to the Lance Armstrong Foundation, mentioned in this article, and has received honoraria for her work with the National Coalition for Cancer Survivorship, also mentioned in this article. Haylock and Curtiss were paid honoraria by AJN for their work as project leaders at an invitational symposium held in Philadelphia in July 2005 and as guest editors of AJN’s March 2006 supplement, State of the Science on Nursing Approaches to Managing Late and Long-Term Sequelae of Cancer and Cancer Treatment. The authors of this article have no other significant ties, financial or otherwise, to any company that might have an interest in the publication of this educational activity. © 2007 Lippincott Williams and Wilkins. No claim is made to U.S. government material.

The degree to which these strategies succeed will depend on whether care planning for survivors becomes routine in cancer care, regardless of discipline or setting. Although research must substantiate the effectiveness of interventions, it's not necessary to wait for that evidence before acting to meet survivors' needs. Much useful information is already available. Evidence can be pursued and consensus guidelines can be developed while survivors' needs are being addressed.

Survivors continue to ask when there will be a consistent approach to survivorship care.

SEQUELAE OF CANCER AND ITS TREATMENT

At present no effective cancer treatment is without adverse effects. Many of these effects are temporary, but others result in chronic health problems that range from mildly annoying to life threatening.⁸ *Late effects* of cancer and cancer treatment include unrecognized toxicities that are absent or subclinical at the end of therapy but manifest later, failure of compensatory mechanisms, and premature aging of organs. They can develop in otherwise healthy survivors months or years after treatment ends. *Long-term sequelae* (also known as *persistent effects*), the adverse effects or complications of treatment, begin during treatment and continue afterward. Late effects, long-term sequelae of cancer and its treatment, or both occur in nearly 75% of survivors.⁸ But little evidence is available to support care planning for long-term survival.^{9,10}

Surgical intervention often results in cosmetic changes and functional impairments. Radiation treatment damages to varying degrees, depending on the dose delivered, any healthy tissues and organs within its field. For example, diminished salivary gland function, consequent nutritional problems and dental decay, and premature vascular disease can result from irradiation of the head and neck; cardiac and pulmonary damage often occurs after radiation therapy for lymphoma or breast or lung cancer. Cytotoxic drugs are associated with significant risks. Alkylating agents, such as the platinum-based compounds, are neurotoxic and nephrotoxic. Antimetabolites such as capecitabine (Xeloda), cytarabine (also known as Ara-C; Cytosar-U, DepoCyt), methotrexate (Rheumatrex, Trexall), fluorouracil (also known as 5-FU; Adrucil), and gemcitabine (Gemzar) cause short-

term diarrhea, mucositis, and skin changes as well as persistent gastrointestinal effects. Antitumor antibiotics such as doxorubicin (Adriamycin and others) are myelosuppressive and associated with cardiac and pulmonary toxicity. Hormonal manipulation is associated with osteoporosis, early menopause, stroke and other clotting abnormalities, and altered sexual function and fertility.

The advent of chemotherapy in the mid-20th century has wrought continuous change in cancer treatment; toxicity profiles are difficult if not impossible to determine. Although the new molecularly targeted therapies such as imatinib mesylate (Gleevec) have shown promise for treating cancer with fewer adverse effects on healthy tissues and organs, the long-term effects are unknown. When a patient with a history of cancer—no matter how long ago—has unexplained symptoms, clinicians should consider the possibility of late effects or long-term sequelae of treatment.

AN AGENDA FOR SURVIVORSHIP

Two decades of advocacy work by the NCCS, the contributions of the Office of Cancer Survivorship (OCS; founded in 1996) of the National Cancer Institute (NCI), and the energy and resources of the Lance Armstrong Foundation (founded in 1997) have provided much of the impetus toward acknowledging and addressing the many unmet needs of cancer survivors.^{7, 11-13} But not nearly enough is being done, according to survivors, advocacy groups, and reports from the President's Cancer Panel, the IOM, the U.S. Centers for Disease Control and Prevention (CDC), and the Lance Armstrong Foundation.^{5, 14, 15}

Nurses and nursing organizations have focused attention on aspects of survivorship that include pain,^{16, 17} sexuality and hormonal and reproductive sequelae,¹⁸⁻²⁰ fatigue,^{21, 22} cognitive function,^{23, 24} familial disruption,^{25, 26} and quality of life.²⁷ But no nursing organization has made survivorship a focus of strategy development, invested significant resources in it, created and delivered products and services specifically for survivors, or substantially participated in cooperative survivorship advocacy efforts.

That said, several health care organizations and professionals have put forward worthy initiatives.

Initiatives. The American Society of Clinical Oncology (ASCO) established a Survivorship Advocacy Group that works to ensure that all ASCO programs consider survivorship issues and that survivorship guidelines are produced, among other things. ASCO's Recommendations on Fertility Preservation in Cancer Patients is free online (www.jco.org/cgi/content/full/24/18/2917), and guidelines on cardiac and pulmonary late effects and hormone deficiency and sexual dysfunction are

A Case Study

Hank Lowry, 72, was diagnosed with prostate cancer seven years ago. (This case is a composite based on our experience.) His initial treatment was antiandrogen therapy with flutamide (Eulexin) and an eight-week course of external beam radiation to the prostate. After radiation therapy was completed, Mr. Lowry continued taking flutamide for two years. After five years without cancer recurrence, he was discharged to his primary care physician for routine care, including annual prostate-specific antigen (PSA) testing and digital rectal examination. Mr. Lowry sometimes delayed his annual visits and tended to schedule appointments only when he had a new problem. His wife initially accompanied him to visits, but when she asked the physician about her husband's occasional urinary incontinence, Mr. Lowry felt embarrassed and annoyed. Thereafter, he went to visits alone.

Six weeks ago, Mr. Lowry sought care from his primary care physician for back pain he described as "tenderness" and a "deep ache" that hadn't responded to over-the-counter (OTC) analgesics or heat. He said he had carried firewood into his house several times in the preceding few days. The physical examination was unremarkable except for generalized tenderness in the lower back, with little restriction in the range of motion. The physician advised Mr. Lowry to continue with OTC analgesics and to try mild stretching. The physician also ordered a PSA test; the result was within the normal range. When Mr. Lowry's symptoms did not resolve within the week, he was referred to an orthopedist who concurred that the back pain probably stemmed from muscle strain and recommended physical therapy.

Both Lowrys were afraid that these symptoms signaled a recurrence of prostate cancer, but neither mentioned

their worry to the primary care physician or the orthopedist. When Mr. Lowry's pain hadn't resolved after four weeks of physical therapy, the orthopedist ordered an X-ray, which showed a compression fracture. A bone mineral density test indicated osteoporosis, a risk for men who are or have been on antiandrogen therapy. Mr. Lowry underwent successful vertebroplasty. His rehabilitation plan included nutritional counseling, exercise planning with a physical therapist, and bisphosphonate therapy. The Lowrys were greatly relieved that the cancer had not returned.

Could Mr. Lowry's back pain, and the Lowrys' emotional turmoil, have been prevented or at least minimized with more timely diagnosis and intervention? Mr. Lowry's history of prostate cancer and antiandrogen therapy puts him at high risk for osteoporosis, as well as for recurrent or metastatic cancer. Upon his discharge from oncology care, a written plan of care for follow-up and health promotion might have helped the Lowrys and the physician anticipate osteoporosis and other late or long-term sequelae, and perhaps to prevent their occurrence. The psychosocial effects of radiation and antiandrogen therapy on urinary and sexual function, as well as their potential impact on the couple's relationship, could have been addressed. Determining whether Mr. Lowry's health insurance would cover screening and office visits might have mitigated his anxiety. And having information about cancer and cancer treatment-related sequelae throughout treatment and during routine follow-up examinations might have helped Mr. Lowry to be more proactive in his care. Such guidance, which nurses can provide in many settings, is a crucial component of what we're calling A Prescription for Living.

pending. The *Journal of Clinical Oncology*, an official ASCO publication, devoted its entire November 10, 2006, issue to cancer survivorship. ASCO has thrown its support behind legislation drafted with the help of the NCCS designed to improve the lives of cancer survivors: the Comprehensive Cancer Care Improvement Act (HR 5465), which was introduced in the House in 2006 by representatives Lois Capps (D-CA) and Tom Davis (R-VA) and is expected to be reintroduced in 2007.²⁸ ASCO's People Living with Cancer (www.plwc.org) Web site offers information to individuals, families, and caregivers. ASCO joins 32 other patient organizations, professional societies, and research organizations on the Cancer Leadership Council, a national forum for discussion and advocacy relating to health policy issues from the perspective of cancer patients and survivors.

The American Cancer Society (ACS) supports the Web-based Cancer Survivors Network (www.accsn.org) and recently published "Nutrition and Physical Activity During and After Cancer Treatment: An American Cancer Society Guide for Informed Choices" in *CA: A Cancer Journal for Clinicians*, with consumer materials set to follow shortly.²⁹

The nonprofit Lance Armstrong Foundation supports education, advocacy, public health programs, and research directed largely toward cancer survivorship. Its Web site, www.livestrong.org, attracts 200,000 visitors monthly. The foundation has contributed nearly \$10 million to cancer survivorship and testicular cancer research³⁰ and partnered with the CDC to help address cancer survivorship issues.¹⁵ In 2006 the foundation established the Livestrong Survivorship Center of Excellence

Table 1. Essential Components of Survivorship Care

1. **Prevention** of recurrent and new cancers, and of other late effects;
2. **Surveillance** for cancer spread, recurrence, or second cancers; assessment of medical and psychosocial late effects;
3. **Intervention** for consequences of cancer and its treatment, for example: medical problems such as lymphedema and sexual dysfunction; symptoms, including pain and fatigue; psychological distress experienced by cancer survivors and their caregivers; and concerns related to employment, insurance, and disability; and
4. **Coordination** between specialists and primary care providers to ensure that all of the survivor's health needs are met.

Hewitt M, et al., editors. *From cancer patient to cancer survivor: lost in transition*. Washington, DC: National Academies Press; 2006. p. 3. Reprinted with permission from the National Academies Press, © 2006, National Academy of Sciences.

Network, a program that supports research and clinical services for cancer survivors at comprehensive cancer centers and affiliated community outreach programs.³¹

The IOM's report. Building on the President's Cancer Panel's 2003–2004 annual report, *Living Beyond Cancer*, and on the joint CDC–Lance Armstrong Foundation report, *A National Action Plan for Cancer Survivorship*, the IOM published a report on the results of a major study of cancer survivorship, *From Cancer Patient to Cancer Survivor: Lost in Transition*, in 2006.⁵ Focusing on survivors of adult cancers after completion of initial treatment, the report seeks to raise awareness of the sequelae of cancer and its treatment, define high-quality health care for survivors and ways to achieve it, and improve the quality of cancer survivors' lives. It makes 10 recommendations⁵:

- Raise awareness of cancer survivorship.
- Provide a care plan for survivors.
- Develop clinical practice guidelines for caring for survivors.
- Define high-quality health care for cancer survivors.
- Overcome health care system challenges.
- Address survivorship as a public health concern.
- Improve the education and training of health care professionals to equip them to care for survivors.
- Address survivors' employment concerns.
- Improve access to adequate and affordable health insurance.
- Invest in research.

There has been little response to this report, except for the recommendation that survivor care planning become routine.⁵ As a follow-up to this report, the IOM and the NCCS, in partnership with the Lance Armstrong Foundation and the NCI, hosted a 2006 workshop, *Implementing Cancer Survivorship Care Planning*, to address several questions. Whose responsibility is it to create survivor care plans? What expertise is necessary for this task? How much time is needed to perform it? And what is to be done about the fact that third-party payors, including Medicare, neither recognize the need for nor reimburse clinicians who provide this service? Also, could any one document developed in care planning sessions enhance communication among clinicians and serve as an information resource and guide for survivors? During this discussion, survivors—many of whom are also clinicians—voiced the need for written information focused on wellness to help them through the “after treatment” phase.

Survivors continue to ask when there will be a consistent approach to survivorship care. No one disputes that the period of watchful waiting that commences after initial cancer treatment—observing for signs of recurrence, for the development of late effects of therapy or the disease itself, for a return to normalcy—is one of emotional turmoil.^{12, 13} The transition from patient to survivor is for many a time of anxiety, uncertainty, and fear.^{5, 14, 32} For many survivors, the old “normal” life never resumes; rather, a new “normal” evolves.^{32, 33}

After initial treatment, survivors typically return to their primary care provider, where follow-up needs may be overlooked³⁴ or the cancer diagnosis itself may shift attention away from screening for other conditions.³⁵ The roles of primary care and specialty providers in survivors' posttreatment care may not be clear.⁹ Care is most likely to be optimal when providers have specialized training in post-cancer care. When care is shared among clinicians and teams at disparate institutions, smooth transitions depend on the transfer of information from specialists to primary care practitioners and patients^{5, 9}; otherwise, primary care providers are poorly prepared. The absence of evidence-based guidelines on disease surveillance, health maintenance, and preventive care further complicates care planning for survivors of adult cancers.

NURSES AND SURVIVORSHIP CARE PLANNING

The 506-page IOM report briefly acknowledges the nurse's role as caregiver to adult-cancer survivors.⁵ Nurse-led (particularly NP-led) models of follow-up care for survivors of childhood cancer are mentioned, as are clinical nurse specialists' contributions to symptom management, continuity of care, dis-

Table 2. Possible Late Effects of Adult Cancers and Their Treatment*

Possible late effects	Agent or modality responsible	Evaluation, screening, and preventive measures†
Any system or area: Recurrence or relapse		
	n/a	Determined based on the site or sites of the original disease
Any system or area: Second malignancies		
Nonmelanoma skin cancer	Chemotherapy and radiation therapy, immunosuppression	Physical examination with biopsy of suspicious lesions; skin photographs may help to monitor status
Breast cancer		Avoidance of excessive exposure to ultraviolet light
Thyroid nodule, thyroid cancer		Mammogram, breast self-examination
Acute leukemia		History and physical examination
Myelodysplastic syndrome		Ultrasound or iodine (¹³¹ I) scan as indicated
Posttransplantation lymphoproliferative disorder		CBC with differential
Cervical cancer		Bone marrow aspirate and biopsy (if CBC is abnormal)
Bladder cancer		CBC with differential
		Bone marrow aspirate and biopsy (if CBC is abnormal)
		CT scans
		Gynecologic examination with Papanicolaou test
		Urinalysis with microscopy to detect microhematuria; urine cytology; follow up positive findings with cystoscopy
Cardiopulmonary system		
Interstitial pneumonitis, bronchiolitis obliterans	Bleomycin (Blenoxane), carmustine (BiCNU), lomustine (CeeNU), busulfan (Busulfex, Myleran), methotrexate (Rheumatrex, Trexall), dactinomycin (Cosmegen), total body irradiation, radiation to the thorax	History and physical examination Assessment for cardiopulmonary comorbidities Smoking cessation counseling Ongoing monitoring for and management of hypertension Consider, as indicated:
Hypertension, cardiomyopathy, pericardial damage, peripheral vascular disease, thromboembolism	High-dose cyclophosphamide (Cytoxan, Neosar), doxorubicin (Adriamycin and others), tamoxifen (Nolvadex), raloxifene (Evista), total body irradiation, radiation to the thorax	<ul style="list-style-type: none"> • Chest X-ray • Pulmonary function tests: lung diffusion capacity and spirometry • Electrocardiogram • Echocardiogram
Mouth		
Sjögren syndrome, caries, periodontal disease, xerostomia, oral malignancy	Radiation therapy to head and neck, chemotherapeutic agents that cause persistent xerostomia (methotrexate, fluorouracil [Acrucil])	Regular dental evaluation; careful attention to oral hygiene; use of fluoride gels or rinses; use of artificial saliva; cessation of tobacco use
Radionecrosis	Radiation therapy	Complete dental exam before beginning bisphosphonate therapy; monitor for soft-tissue fullness around mandible, pain, oral lesions, nonhealing mandibular sores, difficulty with dentures
Osteonecrosis of the jaw	Bisphosphonates	Consider, as indicated: <ul style="list-style-type: none"> • Mandibular CT scan • Biopsy of a nonhealing extraction socket or exposed mandible or maxilla
Endocrine system		
Thyroid: Hypothyroidism	Radiation affecting the thyroid or the hypothalamic-pituitary axis, gonadal failure (infertility) secondary to alkylating chemotherapy, nitrosoureas, procarbazine (Matulane), thalidomide (Thalomid), sunitinib (Sutent)	Consider, as indicated: <ul style="list-style-type: none"> • TSH, T₃, T₄, free T₄ tests • Fasting glucose and lipid profiles • Women: LH, FSH, estradiol, intact PTH, prolactin levels • Men: LH, FSH, intact PTH, prolactin, testosterone levels • Fertility counseling
Gonad: Decreased production of gonadal hormones		
Hypothalamus and pituitary: Abnormal pituitary gland function		
Other		
Metabolic syndrome	Cisplatin (Platinol)	
Steroid-induced diabetes mellitus	Corticosteroids	

Possible late effects	Agent or modality responsible	Evaluation, screening, and preventive measures†
Gastrointestinal system		
Liver dysfunction	Radiation to pelvic fields, methotrexate, carmustine	History and physical examination Consider, as indicated: <ul style="list-style-type: none"> • Endoscopy • CT scans • Small bowel radiography • Liver function tests • Amylase and lipase levels • Fecal fat test • Hepatitis B serologies; hepatitis C PCR test • Laboratory studies (such as CBC, prothrombin time, serum protein determination, alkaline phosphatase) may suggest the presence of dietary nutrient depletion, especially in iron, folate, cobalamin (B₁₂), and vitamins D and K levels; additional studies include measurement of serum carotene, cholesterol, albumin, iron, folate, and cobalamin levels
Malabsorption syndromes, short bowel syndrome, intestinal stricture	Surgery, radiation	
Motility disorders	Vinca alkaloids	
Hepatitis	Blood transfusion	
Genitourinary system		
Radiation nephritis	Radiation	Periodic screening for and aggressive management of hypertension Consider, as indicated: <ul style="list-style-type: none"> • BUN, creatinine levels • Urinalysis with microscopy • 24-hour urine for creatine clearance, total protein
Renal dysfunction, hypertension	Methotrexate, cisplatin, carboplatin (Paraplatin), carmustine, lomustine, certain antimicrobial agents	
Hematuria, proteinuria, bladder scarring, small bladder	Cyclophosphamide, ifosfamide (Ifex)	
Immunologic function and recovery		
Disorders of B and T lymphocyte quantity or functioning, hypogammaglobulinemia, risk of sepsis with encapsulated organisms, suboptimal response to vaccine	Hematopoietic stem cell transplantation, corticosteroids, antithymocyte globulin, methotrexate, alemtuzumab (Campath), rituximab (Rituxan), purine analogs, splenectomy	Baseline and ongoing body temperature assessment; assessment for other indicators of infection (the usual signs and symptoms may be muted by immunologic compromise) Consider, as indicated: <ul style="list-style-type: none"> • CBC with differential • Lymphocyte subsets • Immunoglobulin levels • Vaccination titers
Integumentary system		
Increased incidence of benign and malignant nevi	Radiation therapy, immunosuppression	Physical examination Annual risk awareness counseling Avoidance of excessive exposure to ultraviolet light Biopsy of suspicious lesions
Musculoskeletal system and soft tissues		
Osteoporosis	Chemotherapeutic agents that induce early menopause, antiandrogens, corticosteroids	Physical examination Assess for diminished muscle bulk, tone, and strength; changes in skin (dryness, roughness, hardening); changes in limb circumference; sensation of limb heaviness; presence of edema, discomfort, pain; decreased range of motion Consider, as indicated: <ul style="list-style-type: none"> • Dual-energy X-ray absorptiometry (DEXA) scan • MRI of joint if pain, limited range of motion, or gait disturbance • Evaluation for physical therapy • Exercise assessment and planning • Rehabilitation medicine consultation • Evaluation for lymphedema prevention and management
Avascular necrosis	Corticosteroids	
Muscle atrophy	Radiation	
Soft tissue fibrosis	Radiation	
Lymphedema	Radiation; surgical scarring; biopsy; node mapping procedures; other procedures that compromise lymph node structure, lymphatic flow, or both	

Possible late effects	Agent or modality responsible	Evaluation, screening, and preventive measures†
Nervous system		
Peripheral and autonomic neuropathies	Paclitaxel (Onxol, Taxol), bortezomib (Velcade), thalidomide, vinca alkaloids	Health history Neurologic examination
Cognitive changes (shortened attention span, difficulty with concentration)	Chemotherapy, intrathecal methotrexate	Consider, as indicated: • Neuropsychological testing • Rehabilitation medicine consultation
Leukoencephalopathy	Intermediate or high-dose IV methotrexate or cytarabine (Cytosar-U, DepoCyt)	
Ears		
Ototoxicity	Cisplatin	Consider audiologic testing
Eyes		
Cataracts	Corticosteroids, busulfan, tamoxifen, raloxifene, radiation	Ongoing, regular ophthalmologic examination
Psychology, rehabilitation, and quality of life		
Changes in body image, roles, family relationships, lifestyle, occupation Experiences of discrimination, stigma Fear of recurrence and death	All therapeutic modalities	Systematic, structured assessment of individual adjustment, achievement of normal developmental tasks, marital stress, sexual function, body image, rehabilitation needs, symptom distress

* To read more on these guidelines, see Further Reading: Guidelines and Review Articles on Surveillance and Follow-up at www.nursingcenter.com/qjncancersurvivors. n/a = not applicable; CBC = complete blood count; CT = computed tomography; TSH = thyroid-stimulating hormone; LH = luteinizing hormone; FSH = follicle-stimulating hormone; PTH = parathyroid hormone; PCR = polymerase chain reaction; BUN = blood urea nitrogen; MRI = magnetic resonance imaging

† Few consensus guidelines exist to guide recommendations for evaluation, screening, and prevention of late effects of cancer. Some of these evaluations may not be reimbursable.

ease management programs, and survivorship research. The report suggests that the nurse-led model of survivor care “appears to be promising” despite the limited availability of research for judging its effectiveness.

Nursing’s focus on wellness, health promotion, and supportive care across the lifespan makes nurses well suited to developing and coordinating survivorship care plans. Oncology specialty nurses most often assist patients during initial or primary cancer treatment. Oncology nurses may also be involved in surveillance for treatment-related late and long-term effects. The IOM report comments on the need to strengthen “survivorship content” in graduate nursing programs with an oncology focus, stating that this “could generate more nurses with the training needed to assume active roles in survivorship care.”²⁵ But the management of symptoms related to cancer and cancer treatment falls within the scope of nursing practice, regardless of setting.

A CALL FOR CHANGE IN NURSING PRACTICE

Nurses can coordinate and participate in survivorship care planning by incorporating the components of care highlighted in Table 1, page 62, into routine interactions with patients. Begin by noticing the cancer survivors in your practice area. Look over

For most survivors,
the old ‘normal’ life never
resumes; rather, a new
‘normal’ evolves.

their health histories. Find out what types of cancers are found in your patient population and what types of treatments have been given, taking note of specific drugs, radiotherapy treatment fields, and cumulative doses. Obtain further training and education as needed.

A Prescription for Living. In response to a suggestion made at the November 2006 symposium, we drafted a template to promote routine survivorship care planning. We offer A Prescription for Living (Figure 1, page 67) to nurses and survivors. Although it’s still a work in progress, we believe the template begins to meet the needs of clinicians for a concise summary of treatment and follow-up care

Coming Together to Improve Care

Nursing responds to a new report on cancer survivorship at meeting of 'stakeholders.'

In an effort to better understand the issues and problems related to cancer survivors, *AJN*, in collaboration with the American Cancer Society (ACS), the National Coalition for Cancer Survivorship (NCCS), and the University of Pennsylvania School of Nursing, convened a symposium, State of the Science on Nursing Approaches to Managing Late and Long-Term Sequelae of Cancer and Cancer Treatment, in July 2005. The work produced during the symposium, including recommendations, was published in a supplement to *AJN* (March 2006) and online (www.nursingcenter.com/ajncancersurvivors). Participants at that symposium recommended convening a meeting of key organizational stakeholders to identify appropriate strategies the nursing community can use to enhance outcomes for survivors of adult cancers.

This follow-up meeting, Coming Together to Improve Care: Nursing Responds to the IOM Report on Cancer Survivorship, was held at the National Academy of Sciences in Washington, D.C., on November 3 and 4, 2006, with *AJN* again serving as convener in collaboration with the ACS, the Oncology Nursing Society, and the NCCS. Stakeholder organizations and individuals were asked to collaborate in devising a national nursing organizational plan for implementing recommendations for survivors of adult cancers. A master tactical plan identifying ways nurses can help to improve outcomes among survivors of adult cancers was drafted. The plan is available online at www.nursingcenter.com/ajncancersurvivors.

—Pamela J. Haylock, MA, RN, and Carol P. Curtiss, MSN, RN-BC

planning while also offering survivors a guide for planning healthful lifestyles. Once the template has been used, evaluated, and refined, it should save clinicians time and prevent lapses in care. It can be revised to accommodate different care settings, clinicians, and survivor populations. Empiric studies will be essential to establish its reliability and validity. We encourage nurses to use this template in their practice, and we welcome suggestions for improvement. (Note: As we were going to press, the IOM released its report on the spring 2006 workshop,

Implementing Cancer Survivorship Care Planning: Workshop Summary [www.nap.edu/catalog/11739.html]. The report's implications for survivorship care planning may be useful in refining the Prescription for Living template.)

Oncology nurses in office-based practice settings have begun to incorporate long-term survivor care planning—akin to A Prescription for Living—into routine cancer care. Some have a discussion with patients after initial treatment is finished, asking questions such as “What did we do right?” and “What can we do better?” They also review with patients potential late effects and long-term sequelae of cancer and cancer treatment, self-care strategies, and community-based resources, and reassure them that the cancer team will remain available to them.³⁶ Although nurses outside of oncology settings are at some disadvantage in working with survivors on A Prescription for Living, all nurses can contribute to the process. Many of the data sources mentioned and suggestions provided in this article, including those on assessing survivors' medical histories (see Table 2, page 63), health behaviors, coping strategies, and available resources, can serve as starting points. Scheduling, billing, and reimbursement issues must be addressed, and nurses in primary care settings can provide impetus for change.

You can begin to develop a patient's Prescription for Living plan by using the template at diagnosis or at your earliest interaction. Revise it throughout treatment, and do so again during follow-up. Determining the type of cancer the patient had and the treatment received can help you look for late and long-term effects. Discussing with the patient her or his needs and coping skills will guide your recommendations for other services and referrals.

Talk with your patients about lifestyle factors that affect risk and wellness, such as exercise, diet, and alcohol and tobacco use, and be prepared to offer assistance or make community referrals. Assess for comorbidities that could further complicate long-term sequelae or even affect survival. The ACS recommends a “heart healthy” diet—one low in fat and calories and high in fiber. Most cancer survivors can safely participate in a gentle exercise program that includes both strength and endurance training. For patients with special needs—for example, those who are severely deconditioned or have lymphedema—consultation with a physical therapist or exercise physiologist can be invaluable. Professional rehabilitation, including physical and occupational therapies, is often indicated. Make sure survivors understand how to appropriately use alternative and complementary modalities; many are beneficial, but some can be detrimental. Dietary modifications, acupuncture, massage therapy, specific exercises, relaxation and stress-reduction

Figure 1. A Prescription for Living*

Date of first preparation: _____ Updated: _____

Name:		Date of birth:	Sex:
Cancer diagnosis:		Date of diagnosis:	
Symptoms at presentation:			
Date completed therapy:	Initial stage:	Initial disease site(s):	
History of Cancer Treatment			
Surgery			
Surgeon's name/phone:			
Date:	Procedure:	Pathology:	
Radiation therapy			
Radiation oncologist's name/phone:			
Date range:	Type:	Field:	Dose (in cGy):
Chemotherapy, biotherapy, hormone therapy, targeted therapies			
Medical oncologist's name/phone:			
Regimen 1: _____	Cycles: _____	<input type="checkbox"/> Clinical trial: _____	
Regimen 2: _____	Cycles: _____	<input type="checkbox"/> Clinical trial: _____	
Date range: _____		Date range: _____	
Agents received (include cumulative doses for anthracycline, cyclophosphamide [Cytoxan, Neosar], cisplatin [Platinol], or high-dose therapy)		Agents received (include cumulative doses for anthracycline, cyclophosphamide, cisplatin, or high-dose therapy)	
Transplantation:			
<input type="checkbox"/> Autologous stem cells	Date of transplantation: _____		
<input type="checkbox"/> Allogeneic stem cells	Date of transplantation: _____	<input type="checkbox"/> Related donor	<input type="checkbox"/> Unrelated donor
Other interventions: _____			
Vascular access device: <input type="checkbox"/> Yes <input type="checkbox"/> No Type: _____ Insertion date: _____ Removal date: _____			
Significant events during treatment:			
<input type="checkbox"/> Weight gain > 10 lbs. (4.5 kg)		<input type="checkbox"/> Weight loss > 10 lbs. (4.5 kg)	
<input type="checkbox"/> Cardiopulmonary event: _____			
<input type="checkbox"/> Hemorrhagic cystitis			
<input type="checkbox"/> Psychosocial event requiring treatment:			
<input type="checkbox"/> Major depression		<input type="checkbox"/> Anxiety disorder	<input type="checkbox"/> Other: _____
<input type="checkbox"/> CTCAE grade III or IV toxicities: _____			
Other active health problems: _____ <input type="checkbox"/> None			
Recent disease evaluation:		Date: _____	Testing: _____
Findings:			

Follow-up Plan

Primary cancer care provider:		Symptoms to report:	
Cancer evaluation	Frequency	<input type="checkbox"/> New lumps <input type="checkbox"/> New pain (bone, abdomen, head and neck) <input type="checkbox"/> Bleeding <input type="checkbox"/> Cough that doesn't resolve <input type="checkbox"/> Loss of appetite <input type="checkbox"/> Change in bowel habits <input type="checkbox"/> Weight loss > 10 lbs. (4.5 kg) <input type="checkbox"/> Persistent nausea and vomiting <input type="checkbox"/> Persistent fatigue <input type="checkbox"/> Other: _____	
<input type="checkbox"/> Imaging <input type="checkbox"/> Laboratory <input type="checkbox"/> Physical exam <input type="checkbox"/> Other			
Persistent effects	Plan	Persistent effects	Plan
Physical			
<input type="checkbox"/> Fatigue		<input type="checkbox"/> Anorexia	
<input type="checkbox"/> Pain		<input type="checkbox"/> Weakness	
<input type="checkbox"/> Sleep problems		<input type="checkbox"/> Neuropathy	
<input type="checkbox"/> Urine or bowel dysfunction		<input type="checkbox"/> Continuing blood product and cytokine support	
Persistent effects	Plan		
Other			
<input type="checkbox"/> Onset of functional loss in performing activities of daily living or instrumental activities of daily living			
<input type="checkbox"/> Adjustment problems <input type="checkbox"/> Anxiety <input type="checkbox"/> Depression <input type="checkbox"/> Psychosexual dysfunction <input type="checkbox"/> Other: _____			
<input type="checkbox"/> Inability to return to work or school, or to perform other roles			
Possible late effects of treatment	Plan —Evaluate if patient is symptomatic, follow national guidelines for screening, or consult with oncology team for more information	Possible late effects of treatment	Plan —Evaluate if patient is symptomatic, follow national guidelines for screening, or consult with oncology team for more information
<input type="checkbox"/> Cardiovascular disease		<input type="checkbox"/> Oral dentition, mucosa, bony structures	
<input type="checkbox"/> Second cancer		<input type="checkbox"/> Renal	
<input type="checkbox"/> Hearing loss, tinnitus		<input type="checkbox"/> Neurologic	
<input type="checkbox"/> Hypothyroidism		<input type="checkbox"/> Graft-versus-host disease	
<input type="checkbox"/> Pulmonary dysfunction		<input type="checkbox"/> Infection risk	
<input type="checkbox"/> Cardiomyopathy		<input type="checkbox"/> Osteoporosis	
<input type="checkbox"/> Infertility		<input type="checkbox"/> Psychosocial distress	
<input type="checkbox"/> Hepatic dysfunction			
<input type="checkbox"/> Ocular: cataracts			
Other health care problems	Plan (include provider)		
Wellness	Cancer screening (type and frequency)		
<input type="checkbox"/> Smoking cessation <input type="checkbox"/> Screening for and prevention of osteoporosis <input type="checkbox"/> Screening for and prevention of cardiovascular disease <input type="checkbox"/> Nutrition and healthy weight management <input type="checkbox"/> Physical activity <input type="checkbox"/> Safe sex <input type="checkbox"/> Limiting sun exposure	<input type="checkbox"/> Colonoscopy <input type="checkbox"/> Mammogram <input type="checkbox"/> PSA test and digital rectal exam <input type="checkbox"/> Skin examination <input type="checkbox"/> Papanicolaou test <input type="checkbox"/> Other individualized plan _____		Frequency: _____ Frequency: _____ Frequency: _____ Frequency: _____ Frequency: _____ Frequency: _____
Patient's signature and date:	Clinician's signature and date:		
_____	_____		

* cGy = centigray units, or rads; n/a = not applicable; CTCAE = Common Terminology Criteria for Adverse Events; PSA = prostate-specific antigen

Discussing with the patient her or his needs and coping skills will guide your recommendations for other services and referrals.

strategies, and support groups are some commonly used complementary modalities.

Obtain or compile a list of organizations, groups, and services that may benefit cancer survivors in your community. Include financial assistance programs, social services, dietitians and nutritionists, fitness instructors, credentialed complementary practitioners, support groups, and other services and providers you can recommend with confidence.

Barriers to implementing such interventions will include some that are anticipated and others that are not. A survey of nurses conducted in May 2006 at the Oncology Nursing Society's 31st Annual Congress in Boston offers insight into potential barriers.³⁷ The consensus of focus groups was that nurses could indeed coordinate the development of an interdisciplinary survivorship care plan. Physicians and other team members—such as physical therapists, nutritionists, and social workers—should contribute as well. Specific areas to be attended to include

- addressing the lack of a formal approach to making the transition from patient to survivor.
- increasing awareness that nurses at all skill levels are capable of developing, coordinating, and delivering survivorship care plans.
- allocating time and other resources to developing individualized plans.
- ensuring that reimbursement is commensurate with nurses' expertise and contributions to survivorship care planning.

Looking ahead. How do we establish A Prescription for Living, and the role of nurses in developing and using it, as an accepted part of cancer care? We do it by building on the available reports, the evidence provided in the evolving field of survivorship research, and recent accomplishments. We do it by being partners in multidisciplinary efforts to advance the care of survivors. We do it by putting A Prescription for Living in the hands of *AJN* readers. Start today. The cancer survivors in your work settings and communities will benefit from your efforts.

To view the master action plan *Coming Together to Improve Care for Survivors of Adult Cancers*, from the November 2006 stakeholders' meeting and to see lists of resources for survivors, nurses, and the general public, go to www.nursingcenter.com/ajncancersurvivors. ▼

REFERENCES

1. American Cancer Society. *Cancer facts and figures 2006*. The Society. 2006. <http://www.cancer.org/downloads/STT/CAFF2006PWSecured.pdf>.
2. Rowland JH, et al. Cancer survivorship: a new challenge in delivering quality cancer care. *J Clin Oncol* 2006;24(32): 5101-4.
3. National Coalition for Cancer Survivorship. *Pioneering survivorship: 20 years of advocating for quality cancer care. 2005 annual report*. Silver Spring, MD: The Coalition; 2006.
4. Office of Cancer Survivorship. *About cancer survivorship research: survivorship definitions*. National Cancer Institute, U.S. National Institutes of Health. 2006. <http://dccps.nci.nih.gov/ocs/definitions.html>.
5. Hewitt M, et al., editors. *From cancer patient to cancer survivor: lost in transition*. Washington, DC: National Academies Press; 2006.
6. Leigh S. Myths, monsters, and magic: personal perspectives and professional challenges of survival. *Oncol Nurs Forum* 1992;19(10):1475-80.
7. Lance Armstrong Foundation. *LIVESTRONG poll finds nearly half of people living with cancer feel their non-medical needs are unmet by the healthcare system*. The Foundation. 2004. <http://www.livestrong.org/site/apps/nl/content2.asp?c=jvKZLbMRIsG&b=738963&ct=901209>.
8. Aziz NM, Rowland JH. Trends and advances in cancer survivorship research: challenge and opportunity. *Semin Radiat Oncol* 2003;13(3):248-66.
9. Nielsen JD, et al. Randomised controlled trial of a shared care programme for newly referred cancer patients: bridging the gap between general practice and hospital. *Qual Saf Health Care* 2003;12(4):263-72.
10. Tschirch P. Nightingale on healing. In: Kritik PB, editor. *Reflections on healing: a central nursing construct*. New York: NLN Press; 1997. p. 43-55.
11. Houts PS, et al. Unmet psychological, social, and economic needs of persons with cancer in Pennsylvania. *Cancer* 1986; 58(10):2355-61.
12. Carter SE. End of treatment—laugh or cry? *Community Oncology* 2004;1(3):179-81.
13. Lethborg CE, et al. "Cast adrift": the experience of completing treatment among women with early stage breast cancer. *J Psychosoc Oncol* 2000;18(4):73-90.
14. Reuben SH. *Living beyond cancer: finding a new balance. President's Cancer Panel 2003-2004 annual report*. Bethesda, MD: National Cancer Institute; 2004 May. <http://deainfo.nci.nih.gov/advisory/pcp/pcp03-04rpt/Survivorship.pdf>.
15. Centers for Disease Control and Prevention, Lance Armstrong Foundation. *A national action plan for cancer survivorship: advancing public health strategies*. Atlanta; 2006. <http://www.cdc.gov/cancer/survivorship/pdf/plan.pdf>.
16. ONS to step up research on health care economics. *The Cancer Letter* 1996;22(38):4-6.
17. ONS represented at national summit on cancer pain control. *ONS News* 1997;12(1):8.
18. Thaler-Demers D. Endocrine and fertility effects in male cancer survivors. *Am J Nurs* 2006;106(3 Suppl):66-71.
19. Pelusi J. Sexuality and body image. *Am J Nurs* 2006;106(3 Suppl):32-8.
20. Knopf MT. Reproductive and hormonal sequelae of chemotherapy in women. *Am J Nurs* 2006;106(3 Suppl):60-5.
21. Winningham ML, et al. Fatigue and the cancer experience: the state of the knowledge. *Oncol Nurs Forum* 1994;21(1): 23-36.

22. Barton-Burke M. Cancer-related fatigue and sleep disturbances. *Am J Nurs* 2006;106(3 Suppl):72-7.
23. Nail LM. Cognitive changes in cancer survivors. *Am J Nurs* 2006;106(3 Suppl):48-54.
24. Jansen C, et al. Potential mechanisms for chemotherapy-induced impairments in cognitive function. *Oncol Nurs Forum* 2005;32(6):1151-63.
25. Lewis FM. The effects of cancer survivorship on families and caregivers. *Am J Nurs* 2006;106(3 Suppl):20-5.
26. Mellon S, Northouse LL. Family survivorship and quality of life following a cancer diagnosis. *Res Nurs Health* 2001; 24(6):446-59.
27. King CR, et al. Quality of life and the cancer experience: the state-of-the-knowledge. *Oncol Nurs Forum* 1997;24(1):27-41.
28. National Coalition for Cancer Survivorship. *What is comprehensive cancer care?* The Coalition. 2006. <http://www.canceradvocacy.org/advocacy/comprehensive.aspx>.
29. Doyle C. Nutrition and physical activity during and after cancer treatment: an American Cancer Society guide for informed choices. *CA Cancer J Clin* 2006;56(6):323-53.
30. Lance Armstrong Foundation. *Lance Armstrong Foundation: about us*. The Foundation. http://www.livestrong.org/site/c.jvKZLbMRIsG/b.695471/k.D29D/About_Us.htm.
31. Lance Armstrong Foundation. *Lance Armstrong Foundation establishes Livestrong Survivorship Center of Excellence Network*. The Foundation. 2006. <http://www.livestrong.org/site/apps/nl/content2.asp?c=jvKZLbMRIsG&b=738961&ct=2085341>.
32. Harpham WS. *Happiness in a storm: facing illness and embracing life as a healthy survivor*. New York: Norton; 2005.
33. Haylock PJ. The shifting paradigm of cancer care. *Am J Nurs* 2006;106(3 Suppl):16-9.
34. Ganz PA. Monitoring the physical health of cancer survivors: a survivorship-focused medical history. *J Clin Oncol* 2006;24(32):5105-11.
35. Earle CC, Neville BA. Under use of necessary care among cancer survivors. *Cancer* 2004;101(8):1712-9.
36. Curtiss CP, et al. Improving the care of cancer survivors. Anticipating, assessing for, and managing the effects of cancer and its treatment. *Am J Nurs* 2006;106(3):48-52.
37. Harvey C. *Perspectives on survivorship care planning: presentation of IOM commissioned qualitative research: nurses*. Workshop on Implementing Cancer Survivorship Care Planning. An Institute of Medicine, National Cancer Policy Forum Workshop Sponsored by the National Coalition for Cancer Survivorship in Partnership with the Lance Armstrong Foundation and the National Cancer Institute, May 15; Washington, DC. <http://www.iom.edu/CMS/26765/39406.aspx>.



3.5 HOURS

Continuing Education

EARN CE CREDIT ONLINE

Go to www.nursingcenter.com/CE/ajnl and receive a certificate within minutes.

GENERAL PURPOSE: To provide registered professional nurses with information on a multidisciplinary approach to cancer survivorship, as well as "A Prescription for Living," a template clinicians and patients can use for individualizing care for cancer survivors.

LEARNING OBJECTIVES: After reading this article and taking the test on the next page, you will be able to

- list the common characteristics of cancer survivorship.
- discuss the various initiatives that have addressed the issues involved with cancer survivorship.
- outline the most common persistent and late effects of cancer and its treatment.

TEST INSTRUCTIONS

To take the test online, go to our secure Web site at www.nursingcenter.com/CE/ajnl.

To use the form provided in this issue,

- record your answers in the test answer section of the CE enrollment form between pages 48 and 49. Each question has only one correct answer. You may make copies of the form.
- complete the registration information and course evaluation. Mail the completed enrollment form and registration fee of \$27.95 to **Lippincott Williams and Wilkins CE Group**, 2710 Yorktowne Blvd., Brick, NJ 08723, by April 30, 2009. You will receive your certificate in four to six weeks. For faster service, include a fax number and we will fax your certificate within two business days of receiving your enrollment form. You will receive your CE certificate of earned contact hours and an answer key to review your results. There is no minimum passing grade.

DISCOUNTS and CUSTOMER SERVICE

- Send two or more tests in any nursing journal published by Lippincott Williams and Wilkins (LWW) together, and deduct \$0.95 from the price of each test.
- We also offer CE accounts for hospitals and other health care facilities online at www.nursingcenter.com. Call (800) 787-8985 for details.

PROVIDER ACCREDITATION

LWW, publisher of *AJN*, will award 3.5 contact hours for this continuing nursing education activity.

LWW is accredited as a provider of continuing nursing education by the American Nurses Credentialing Center's Commission on Accreditation.

LWW is also an approved provider of continuing nursing education by the American Association of Critical-Care Nurses #00012278 (CERP category O), District of Columbia, Florida #FBN2454, and Iowa #75. LWW home study activities are classified for Texas nursing continuing education requirements as Type 1. This activity is also provider approved by the California Board of Registered Nursing, provider number CEP 11749, for 3.5 contact hours.

Your certificate is valid in all states.

TEST CODE: AJN0807