

Coming Together to Improve Care for Survivors of Adult Cancers

The Master Action Plan from the November 2006 stakeholders' meeting in Washington, D.C.

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

Goal #1. To build the capacity to educate all nurses, caregivers, patients, and the public on cancer survivorship issues, including undergraduate and graduate curricula and continuing education.

Strategy	Responsible Organization
1. Convene a small group of experts to review the plan described below and identify current models in order to avoid duplication of efforts.	The Oncology Nursing Society (ONS) will explore convening a meeting along with Sigma Theta Tau International (STTI) and the National Coalition for Cancer Survivorship (NCCS) to determine the next steps in moving this initiative forward.
2. Establish separate task forces for nursing education, caregiver education, patient education, and public education. Each will address the following: <ol style="list-style-type: none"> a. Assessment phase: Identify resources currently available and identify gaps in resources. <ol style="list-style-type: none"> i. Literature review on cancer survivorship and models of care delivery. b. Seek assistance from organizations to evaluate undergraduate and graduate curricula. As assessment proceeds, increased awareness will be a by-product. As the process moves forward, connect with communications experts to send broad messages about nursing's role in cancer survivorship, including public service announcements (PSAs). 	The ONS will explore doing so for continuing education (CE) and may assist on PSAs. The NCCS has agreed to direct the public education assessment.
3. Appeal to the Nursing Organization Alliance ("the Alliance") for collaboration and action: <ol style="list-style-type: none"> a. Conduct an online survey of the Alliance's member organizations. <ol style="list-style-type: none"> i. Understanding of cancer survivorship issues. ii. Work being done by specialty groups. b. Present findings at the Alliance next year. c. Obtain the Alliance's commitment to educate members about cancer survivorship, offer available resources (for example, Tool Box, one hour CE course). 	The ONS and STTI have agreed to raise this issue.

Strategy	Responsible Organization
4. Identify groups that are not part of the Alliance (for example, home care, hospice, ambulatory care, visiting nurses) and seek their involvement.	To Be Determined
5. Seek corporate and other partnerships for funding. a. National Cancer Institute, U.S. Administration on Aging, AARP, Johnson & Johnson, Lance Armstrong Foundation	To Be Determined
6. Identify additional partners who need to be "at the table."	To Be Determined
7. Create an action timeline for completion of work.	The NCCS: Initiate an active process that pushes survivorship issues into nursing practices.
8. Develop a core curriculum based on a train-the-trainer model for educating health care professionals, using the Institute of Medicine (IOM) and City of Hope National Medical Center Curriculum for Survivorship and the End-of-Life Nursing Education Consortium as models. Build in the ability to adapt the curriculum for specific organizations.	The American Nurses Credentialing Center (ANCC): Will partner with other nursing organizations to produce leading-edge CE curricula and pledge to attend their conferences, and to promote collaborative presentations with other organizations. Will involve the Magnet chief nursing officer and the research community through our online networks and at the national Magnet conference. Ask them to incorporate cancer survivorship into their community involvement. The STTI: Will link subsidiary Nursing Knowledge International to efforts to disseminate CE, course or modules, and standards as developed (may be electronic- or print-based materials).
9. Work with insurance companies and employers.	The American Association of Occupational Health Nurses will lead this strategy.
10. Partner with nursing organizations and the Magnet community to develop a "traveling education module." a. Provides CE contact hours for nurses. b. Slide show, IOM video, speakers and champions, Web sites, bibliographies	The American Association of Colleges of Nursing (AACN): Will have a section on the AACN Web site for nursing faculty regarding cancer survivorship issues, PowerPoint slides for lectures, supplemental teaching materials (such as case studies), updated reference list including research-based publications.
11. Once graduate and undergraduate curricula are evaluated, offer flexible, user-friendly course work that can be shaped into summer courses, faculty-led Internet-based courses for college credit or online CE. Consider creating Podcasts available for download.	To Be Determined
12. Identify schools with exemplary curricula on cancer survivorship as models.	AACN
13. Seek out the participation of the American Organization of Nurse Executives.	To Be Determined
14. Work to increase the content on cancer survivorship available in nursing texts and certification exams.	The ANCC: Will incorporate cancer survivorship content in certification exams wherever feasible.
15. Patient and caregiver education a. Create patient education card for lifelong follow-up as a companion to the "Prescription for Living" portion of a survivor plan of care. b. Place this card online available for download. c. Encourage initiation of the card at the first post-op visit, or early in other treatment schedules. d. Be sure that the resource is culturally sensitive and appropriate for diverse populations. e. Make online resources available for patients and caregivers. f. Identify (and possibly publish) resources currently available for patient and caregiver education. 16. Public education a. PSAs, perhaps in partnership with Johnson & Johnson. i. Focus on life after cancer treatment. ii. Care must be seen as lifelong and merged with lifelong healthful lifestyle choices. iii. Sub-focus on "your new normal" and the need to stay well. iv. "Take care of your health."	Include social work organizations, cancer care groups, the American Nurses Association, and the ONS Special Interest Group.

Strategy	Responsible Organization
17. Establish a plan for media outreach to promote this work.	To Be Determined
18. Disseminate information about the stakeholders' meeting and survivorship work through organizations' publications.	<p>The AACN: Announce the survivorship work (and its process) in a monthly e-newsletter that the AACN sends to more than 10,000 deans of nursing, nursing faculty, nursing organizations, government leaders, and other stakeholders.</p> <p>The American Academy of Ambulatory Care Nurses (AAACN): Raise awareness among AAACN members with an article in <i>Viewpoint</i> (its membership newsletter) linking care of adult cancer survivors and the ambulatory care setting; include highlights from this meeting (proposed tasks included "a call to action") and provide a list of available resources for more information.</p> <p><i>AJN</i>: Publish editorial "call to action" and article on cancer survivorship and the "Prescription for Living" in the April issue. Include models, put online links to <i>AJN</i> survivor page at both www.ajnonline.com and www.nursingcenter.com/ajn. Press release announcing the stakeholders' work—send to all stakeholders to publish as well. Press release and media outreach strategy for April issue. In April 2008 will announce progress.</p> <p>The American College of Nurse Practitioners (ACNP): Ask for national call for change. Will send e-mails and letters to members to acknowledge need for survivorship issues and content. Will incorporate cancer survivorship into Virginia Council of NPs meeting (plan in place now) and report to ACNP the form and format. Summary of this meeting to ACNP leadership.</p> <p>The ANCC: Will summarize what nursing has agreed to regarding cancer survivorship and create links to Web sites that carry specific content. In our message, we'll encourage practicing nurses, students (both graduate and undergraduate), administrators, educators, and consumers to scan the Web sites systematically and periodically and to offer the ANCC feedback online on the usefulness and application. Will instruct staff directors and our 700 annual volunteers in cancer survivorship and invite all to incorporate this new knowledge into their daily practice. Wherever possible the messages will include survivor testimonials to underscore the importance of this work. Will think about how to involve our international constituents as well.</p> <p>The International Society of Nurses in Cancer Care: Publish article in ISNCC newsletter on this work and potential issues for international cancer nursing community.</p> <p>The STTI: Publish article in <i>Reflections</i> (an STTI publication) regarding survivorship and collaboration between nursing organizations. E-mail push to members as plans and resources are developed directing them to sites. Approach the <i>Journal of Nursing Scholarship</i> regarding a series on the topic. Symposium at STTI convention on research practice education.</p> <p>Society of Gynecologic Nurse Oncologists: Incorporate cancer survivorship content into <ul style="list-style-type: none"> • textbook to be published in 2007 (specific to gynecologic oncology). • 2007 symposium and yearly thereafter. • at least one journal article on cancer survivorship in 2007 and one per year thereafter. Request that survivorship concept be incorporated into mission statement and strategic plan.</p>

Goal #2. In collaboration with patients and families, develop a jointly crafted, interdisciplinary, evidence-based wellness plan as part of a comprehensive cancer survival care plan.

Strategy	Responsible Organization
1. Convene a working group to review current plans of care and draft a template including core components for the “Prescription for Living” portion of the survivor care plan. <ul style="list-style-type: none"> a. Interdisciplinary and evidence-based b. Individualized to patient and family c. Applicable in a variety of formats and at various education levels d. Translatable to a variety of settings e. Initiated at the time of diagnosis f. Information “phased” according to treatment and recovery style g. Future-focused and revisited over the continuum of survivorship 	The National Institutes of Health Clinical Center, Nursing and Patient Care Services: Will support the contribution of advanced practice nurse time and expertise for the creation and publication in a forthcoming issue of <i>AJN</i> of a cancer survivorship care plan that is evidence based and wellness focused.
2. Publish a call for change within the nursing community and reach out to others. <ul style="list-style-type: none"> a. Appeal to the Alliance and within individual organizations to communicate with their board of directors. b. Create awareness among members of nursing organizations by including survivorship issues at national meetings. c. Work with state cancer plans to “drill down” into survivorship-specific needs. d. Encourage organizations to support Comprehensive Cancer Care Improvement Act of 2006 (HR 5465), which is seeking reimbursement for survivorship care planning. e. Write a white paper or position statement and reach out to the media. 	The ONS and STTI: Will raise the issue with the Alliance. The AACN: Will include survivorship content at conferences.
3. Review and repurpose existing products to include a survivorship component.	To Be Determined
4. Disseminate the report from the stakeholders’ meeting to all nursing organizations (presidents, boards of directors, executive directors), hospitals, State of the Science meeting participants (from the July 2005 meeting), the Commission on Cancer, the American College of Surgeons, the American Society of Clinical Oncology, the Joint Commission, the Association of Community Cancer Centers, pharmacology companies, Cancer Leadership Council, and US Oncology.	AJN: Will make the report available online at www.nursingcenter.com/ajncancersurvivors .
5. Ensure that scope of practice statements include cancer survivorship	To Be Determined

Goal #3. Develop and prioritize a multinational research agenda related to cancer survivorship and translate the findings into clinical practice and policy.

Strategy	Responsible Organization
1. Use the IOM Report and the <i>AJN</i> article as the foundation for international research agenda.	

Strategy	Responsible Organization
<p>2. Identify organizations willing to assume leadership or accountability to convene a meeting of key stakeholders to establish and prioritize a specific research agenda for nursing including each of the following areas of inquiry:</p> <ul style="list-style-type: none"> a. Nature and scope of the problems and issues related to survivors of cancer. <ul style="list-style-type: none"> i. Evaluate published reports (the IOM and <i>AJN</i>) to determine if problems listed are the appropriate problems and issues. ii. Write a specific, detailed, and prioritized research agenda. iii. Include those who provide funding (American Cancer Society, Lance Armstrong Foundation), survivors (across all age groups and diagnoses), doctoral students, policy and decision makers, legislators, nurse researchers, patients, NPs, and primary care providers. iv. Determine the survivor population at greatest for research that would have the greatest impact—who it affects, what it costs, and quality of care. <ul style="list-style-type: none"> 1. comorbidity 2. high risk of recurrence 3. high risk of toxicity 4. high distress at time of completion of therapy 5. psychosocial risk 6. ethnic or cultural b. Access to care. c. Outcomes of survivors. <ul style="list-style-type: none"> i. What are the outcomes or benchmarks of survivors that should be monitored? ii. Are there clusters of issues to examine? d. Education and dissemination of information. <ul style="list-style-type: none"> i. Determine if a clearinghouse exists to disseminate information to all providers to help ensure that quality care is delivered. 	<p>The STTI: Will collaborate with the ONS and the ISNCC to convene a meeting of scholars in survivorship research to set agenda going forward to identify grant priorities in collaboration with the ONS and larger funding sources.</p> <p>The ISNCC: Propose to work with the ONS and the STTI as leaders on the research agenda and plan.</p> <p>The STTI can help establish an electronic communication vehicle after this stakeholders' meeting and can provide an infrastructure for some research efforts.</p> <p>The ISNCC: May also be able to help to establish a research clearinghouse on the ISNCC Web site.</p>
<p>3. Identify the opportunities for collaborative grants.</p>	<p>The Agency for Healthcare Research and Quality (AHRQ): Will work to fund research to improve the quality of care and outcomes for cancer survivors.</p>
<p>4. Identify and discuss models for collaborative multisite research such as the STTI's AIDS collaborative work or the "Communities of Practice" model.</p>	<p>The STTI, the ISNCC, and the ONS</p>
<p>5. Issue a call for multisite research related to cancer survivorship.</p>	<p>The AHRQ: Will work with potential investigators to address research gaps in clinical knowledge to improve outcomes and quality care for cancer survivors. This would include research related to translational investigators.</p>
<p>6. Identify a top-level leader who can step in where <i>AJN</i> has been in this effort to coordinate goals. 7. Identify stakeholders, true operational players who will move the agenda forward.</p>	<p>The STTI is committed to moving this forward and will work with the ONS and the NCCS to explore the next steps.</p>
<p>8. Establish facilitated workshops to prepare researchers to complete quality research in this area.</p>	<p>To Be Determined</p>
<p>9. Establish a program for senior researchers to mentor novice researchers and to educate collaborators and economists.</p>	<p>To Be Determined</p>
<p>10. Using the ONS Putting Evidence into Practice initiative as a model, establish an initiative that looks at what is known that can be applied to practice and how this information can be coordinated and disseminated to both non-oncology and oncology nurses.</p>	<p>To Be Determined</p>

Individual Organization Plans

Please use any of these activities for your organization as well.

American Academy of Ambulatory Care Nurses (AAACN): Ask for commitment and consideration of the following:

- Survivorship issues incorporated into agendas both locally and nationally.
- Cancer survivorship session offered at annual meeting.
- Identify local "experts" for presentation at local- and regional-level meetings.
- Faculty-led, Internet-based course for continuing education (CE) credit on the AAACN Web site.
- Utilize AAACN public relations expert to maintain a consistent and ongoing message related to cancer survivorship issues.

American Association of Colleges of Nursing (AACN):

- Write an article for *Journal of Professional Nurses* for nursing faculty that provides information on survivorship curricula that already exist, Web sites, and other Internet-based information.
- Place updates on survivorship and coalition in the monthly AACN e-newsletter, *News Watch*.
- Use the AACN Web site to present survivorship issues to nursing faculty, to post lecture slides, and to provide updated references and research-based publications.

American Association of Occupational Health Nurses (AAOHN): Recommend the following items to Ann Cox, executive director of the AAOHN:

- Newsletter article to increase awareness.
- Discuss at the board level if to add cancer survivorship to the AAOHN statement regarding key public policy issues.
- Links to resources on the AAOHN Web site.
- Considerations to include survivorship as a component in AAOHN ends and subends.
- Embrace an educational approach via an AAOHN-endorsed study module (which includes a video and talking points) to allow local chapters and state organizations to educate their membership on issues related to cancer survivorship.
- Establish the AAOHN as a leading resource to work with employers (and their professional organizations) to increase awareness and to provide resources regarding cancer survivorship.

American College of Nurse Practitioners:

- Will collaborate on an article on cancer survivorship.
- Write cancer survivorship proclamation format and op-ed for local papers.

AJN:

- Submit abstract to the International Academy of Nurse Editors or post message on their listserv regarding the plan and call to action and coverage.
- Nancy Houlihan sidebar on Goldman Sachs and counseling on getting back to work.
- Coordinate article and editorial on this initiative (the call to action) and publish sample "Prescription for Living" in the April issue and post the master plan online.
- Work to transition this initiative to organizations that will take the lead.

Association of Oncology Social Work (AOSW): Will take back to their board:

- Newsletter article about this stakeholders meeting to discuss one of the outcomes: The *AJN* article that will have models

of interdisciplinary survivorship care plans that include addressing psychosocial issues; developed for and with patients and their family and caregivers (newsletter will reach more than 1,000 AOSW members).

- Revision of the AOSW Web site (early 2008) to include survivorship content under the patient and caregiver section.
- Alert nursing colleagues and organizations when our POWER (Psychosocial Oncology Worldwide Educational Resource) database is established that identifies oncology social workers who have experience in teaching, educating, or providing support either by topic or geographic location. Could be used as a resource when completing survivorship plans.

International Society of Nurses in Cancer Care (ISNCC):

- Bring this issues forward to ISNCC board for commitment and plan for next steps.
- Cancer survivorship is a theme at 15th ISNCC and will profile this issue at the international level.

National Association of Clinical Nurse Specialists (NACNS): Will discuss with the NACNS board:

- Bring a "call to action" or "call to change" to the NACNS board and request that the board place cancer survivorship issues on the strategic plan.
- Collaborate with other organizations to contribute to a white paper on cancer survivorship issues to call to action.
- Collaborate with the Oncology Nursing Society (ONS) to help develop nursing CE programs regarding cancer survivorship.
- Ask the NACNS board to identify appropriate contributors to a white paper.
- Ask the NACNS board to identify appropriate contributors to develop nursing CE programs in collaboration with the ONS.

National Association of Social Workers:

- Advise nursing on models of developing and disseminating professional and consumer education.
- Link to social work researchers for future collaborative interdisciplinary research.
- Provide consultation and peer review regarding development of interdisciplinary care plans.
- Continue to advocate and lobby for policies and legislation supporting timely access to appropriate medical care for persons with cancer, including survivors.

National Coalition for Cancer Survivorship (NCCS):

- Can link to others' nursing resources.
- Is interested in committing to the development of nursing partnerships and would consider being co-convenor of the group.
- Can bring survivors into the process to respond to products and submit proposals from the patient's point of view.
- Can make the Institute of Medicine report and video available: *From Cancer Patient to Cancer Survivor: Lost in Transition*.
- Can make survivor tool box available.
- Can contribute editorials and articles from the survivor's perspective.
- Will continue to lobby for Comprehensive Cancer Care Improvement Act of 2006 (HR 5465), legislation that will help future funding for cancer care.

ONS:

- Publish on the ONS Web site a link to the April AJN survivorship article.
- Ask editors of the ONS journals to consider an article on survivorship.
- Ask an ONS board member how to craft a message for people in the mass media, such as Oprah Winfrey.
- Also find out how the nursing community can get the media interested in this issue.
- Explore collaborating with NCCS and Sigma Theta Tau International (STTI) to be co-convenor of survivorship next step meeting.
- Assess current CE offerings on survivorship.
- Self-assessment of current CE publications on survivorship.
- Ask the Alliance to send out survivorship survey in 2008 that is based on the National Comprehensive Cancer Network's focus group work.
- Ask for permission to give presentation of the Alliance reports of the survey.
- Ask for commitment from each organization to provide information to their members on cancer survivorship.
- Survey to assess inclusion of content on cancer survivorship in various ONS publications and whether or not a survivorship model can be identified.
- One half-day CE program at the ONS Leadership Institute. Separate CE for POS cards, Webcasts, and others.

STTI:

- Co-convene coalition to advance survivorship.

Society of Gynecologic Nurse Oncologists (SGNO):

- "A Prescription for Living" template and content for a brochure to distribute through gynecology and oncology offices through the Gynecologic Cancer Foundation. Target date for implementation is the fourth quarter of 2007.
- Possibly incorporate the brochure into their Web site (www.SGNO.org) and Women's Cancer Network (www.WCN.org)
- Further explore multidisciplinary research on gynecologic oncology survivorship through collaboration with gynecologic oncologist organization memberships and survivors' networks.

Philippine Nurses Association:

- Present summary of this meeting and bring back materials including a hard copy of the presentations to the board.
- Suggest cancer survivorship as a topic at annual convention and bring forward to international conference and connections; invite one of the nurses in a lead role as a speaker; follow up during regional conferences on progress, reports, where are we, and so on.
- Disseminate information about cancer survivorship to all chapter presidents and suggest they include it in education program (tools, video, survey, and so on) offering CE credit.
- Chapter presidents will encourage members to join cancer organizations and participate in different programs.
- Proposal for commitment will be presented to the board.
- State chapter to provide CE information and resources to community via literature community meetings and collaborate with different community organizations and churches.
- Include information in newsletter to create awareness of cancer survivorship.

Individual Plans

The following individuals were key contributors at the stakeholders' meeting.

Individual	Responsibility
Regina Cunningham, The Cancer Institute of New Jersey, New Brunswick	<ul style="list-style-type: none"> • Individual goals: Cunningham will spearhead the development of a center for survivorship at the institute where she works (there are currently efforts underway but they are not organized, including bringing researchers in population, clinical, and basic science together. She will also earmark research funds within the organization to survivorship studies and expand to multisite research. • Participate in further developing the research agenda, particularly as it relates to cancer survivorship. • Participate in developing the educational agenda. • Speak with communications regarding public education by radio and other media. • Connect to primary care: will meet with chair and discuss how they can collaborate. • Address leadership council (board level) regarding survivorship issues; they have a large role in fund-raising.
Nancy Houlihan, Memorial Sloan-Kettering Cancer Center (MSKCC), New York City	<ul style="list-style-type: none"> • Contribute to the immediate development of care plan. • Share the materials we have developed in our survivorship care model as a Lance Armstrong Foundation LIVESTRONG Survivorship Center of Excellence Network. • Contact the nurses at these centers to organize to support our efforts. • Inform the MSKCC public affairs office about this meeting and nursing plan for cancer survivorship. ▼