

Alaska

Cancer Survivorship Resource Plan

2013



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Alaska Comprehensive Cancer Control Cancer Survivorship Resource Plan 2013: Addressing the Needs of Alaska Cancer Survivors



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What is Comprehensive Cancer Control?

The Centers for Disease Control and Prevention (CDC) defines comprehensive cancer control (CCC) as a collaborative process through which a community pools resources to reduce the burden of cancer that results in risk reduction, early detection, better treatment, and enhanced survivorship.

CDC's National Comprehensive Cancer Control Program (NCCCP) provides initial funds to help states, tribes, and territories to establish CCC coalitions, assess the burden of cancer, determine priorities, develop and publish CCC plans, and evaluate success of plan implementation. The Alaska Department of Health and Social Services received its first grant from the CDC to commence comprehensive cancer control planning in September 2003. In 2006, Alaska's Comprehensive Cancer Control Program was designated as an implementation program by CDC, and, in partnership together with the Alaska Comprehensive Cancer Partnership, began implementing the Alaska CCC Plan.

Link to AK CCC Plan:

<http://dhss.alaska.gov/dph/Chronic/Documents/Cancer/assets/ACCCP.pdf>

What is a Resource Plan?

The Alaska CCC Program receives funding from CDC to support the infrastructure needed to maintain a CCC coalition, to maintain a current CCC plan and to evaluate the results of plan implementation. Resources to support implementation of the CCC plan come from many sources, including members of the CCC coalition, local/state/federal governments, and interested donors and foundations. Understanding and communicating resources needed to implement CCC plan priorities is a key step in CCC plan implementation. The purpose of a resource plan is to provide current and potential partners and supporters with the information they need to make an investment in helping to implement CCC plan priorities – from providing direct funding to leveraging existing resources to meet priority needs.

Why Focus on Resources Needed for Survivors?

The Alaska Comprehensive Cancer Partnership identified addressing the needs of cancer survivors as a priority because of the growing numbers of survivors in Alaska, and their unique needs. Currently it is estimated there are 13 million people who have had cancer or are living with cancer in the United States and an estimated 30,000 cancer survivors in Alaska.¹ The term “cancer survivor” refers to those people who have been diagnosed with cancer and the people in their lives who are affected, including family members, friends, and caregivers. As survival rates increase, the long-term effects of cancer and cancer treatment are being realized. Cancer is emerging as a chronic health condition, rather than a terminal disease. Cancer patients need to be aware of and how to advocate for future care related to their past cancer treatment.

¹ American Cancer Society. *Cancer Treatment and Survivorship Facts & Figures 2012-2013*. Atlanta: American Cancer Society; 2012.

The challenges facing Alaska cancer survivors include the following:

- High travel costs to access necessary medical care and follow-up services
- Lack of survivor-focused programs and support in sparsely populated communities
- Lack of information about and understanding of long-term effects of cancer treatments
- Lack of provider knowledge regarding issues effecting cancer survivors

Addressing these challenges requires innovative solutions. For all these reasons, the AK CCC plan includes the following priority related to survivorship:

Ensure all Alaskan cancer survivors have equal access to information, and follow-up medical, rehabilitative and psychosocial services.

To help address this priority goal the Alaska Comprehensive Cancer Partnership is focusing this resource plan on the unique needs of Alaska cancer survivors. By focusing attention on needs and leveraging existing cancer survivorship programs and knowledge, the Partnership hopes to accelerate the pace of addressing cancer survivor needs in the state.

How This Resource Plan Was Developed

The Alaska Comprehensive Cancer Control Program and the Alaska Comprehensive Cancer Partnership developed this resource plan, with leadership from the Partnership's Survivorship Committee, and assistance from Strategic Health Concepts, a consulting company.

The information included in this resource plan was developed through the following: 1) a review and comparison of cancer survivor care and support national guidelines and evidence-based practices and current Alaska programs and activities to identify gaps, and; 2) key informant interviews designed to gain a better understanding of what is working well and needs to be improved to address cancer survivor needs in the state. Using this information, the Alaska Comprehensive Cancer Partnership prioritized the following actions to address critical cancer survivor needs.

Making a Difference in the Lives of Cancer Survivors: Priorities for Action and Resources Needed

The following four actions were prioritized by the Alaska Comprehensive Cancer Partnership to address cancer survivor needs:

1. **Develop new and expand current successful culturally and geographically appropriate programs for cancer survivors.** While there are several well-designed cancer survivor support programs in the state, they are mainly centered in larger cities and may not take into account all the diverse needs of special populations. Existing programs, such as "New Norm" (a successful cancer survivor education and information program), could be expanded and offered in other geographic locations for specific populations.

2. **Promote evidence-based clinical practice guidelines related to cancer survivor care among primary care providers.** Increased education for primary care providers is needed to ensure providers understand the needs of their patients from the moment of diagnosis and referral to oncology services to the moment they return to primary care as a cancer survivor.
3. **Enhance survivor navigation services offered statewide.** Navigation or guiding a cancer patient through their care must begin from the moment of diagnosis and continue through the patient’s life. Current cancer survivor navigation services are limited in the state.
4. **Encourage the use of survivor care plans.** New and longer-term cancer survivors need to work with their care providers to develop and use survivor care plans that summarize their cancer treatments and provide information about what to expect and how to manage the effects of cancer treatment that occur later in the cancer survivor's life.

The following table provides an estimate of the resources needed to address the four priorities just described. The table includes a description of specific actions needed to achieve the priority, the type of resources needed, and a specific amount of funding and/or in-kind resources needed. The costs (such as salaries, contracts and specific costs to develop or deliver a program, etc.) are based on similar costs in Alaska.

Actions to Achieve Priority	Type of Resources Needed to Take Action	Funding Needed	In-Kind Resources Needed
<i>Priority 1: Develop and expand culturally and geographically appropriate programs for cancer survivors</i>			
Create a resource list of existing programs, support services, both statewide and by individual region or community; establish a place for this online	Website or web portal development, promotion and maintenance	Approximately \$15,000 for site development	Part-time staff to maintain website
Create a video series of stories for different populations from cancer survivors, families, caregivers; distribute to providers and others for education purposes	Story development, video recording services, distribution and promotion	Digital storytelling \$3,500 per session; total \$35,000	Computer expertise, video recording services
Recruit and support cancer survivors from specific populations to be “ambassadors” to reach out to other survivors	Ambassador program development, materials development (e.g. community resource book), recruitment of survivors, support for ambassador travel to meetings and training	Grant to community-based organization to develop and maintain ambassador program, with a goal of 13 ambassadors; total \$24,000	Recruitment and training of volunteers
Celebrate and recognize diverse cultures by using art and storytelling to get the word out about cancer survivor needs and resources	Identification and development of cancer survivor art and stories, printing costs	Printing costs for 150 soft cover books, approximately \$5,000	Identifying artists and collecting art, photos of art, exhibition space, development and promotion of exhibit

Actions to Achieve Priority	Type of Resources Needed to Take Action	Funding Needed	In-Kind Resources Needed
Priority 1: Develop and expand culturally and geographically appropriate programs for cancer survivors (CONTINUED)			
Create a toolkit for communities who want to develop new cancer survivor support groups	Adaptation of existing toolkits for Alaska, distribution and promotion of toolkits	Approximately \$15,000 for contract or grant for toolkit adaptation, development	Distribution and promotion of toolkits
Expand New Norm to small communities with inclusion of education topics that are relevant to diverse populations	Development of additional sites, recruitment of local community volunteers, travel costs for speakers	\$850 per New Norm series added	Recruitment of local volunteers to assist; Hosting of New Norm program (space, equipment, food)

Actions to Achieve Priority	Type of Resources Needed to Take Action	Funding Needed	In-Kind Resources Needed
Priority 2: Promote evidence-based clinical practice guidelines related to cancer survivor care among primary care providers			
Identify national clinical practice guidelines to promote, as well as develop recommendations for providers regarding discussing the cost and benefits of treatment and impact on quality of life with the cancer patient as part of the decision-making process	Identification and assessment of national guidelines, facilitation of partner involvement in making decisions about which guidelines to promote and what recommendations to make, packaging guidelines for distribution and promotion	Approximately \$20,000 for a consultant	Partner time and involvement in identifying guidelines and recommendations
Promote national clinical practice guidelines and recommendations regarding shared decision-making with cancer survivors	Distribution of guidelines and recommendations	NA	Masters level student to help with promotion
Offer workshops for primary care providers regarding cancer survivor care	Training development costs, travel costs for provider champions to participate, continuing medical education (CME) costs	Approximately \$20,000 for training development and delivery	Travel costs for provider champions, training space, CME costs

Actions to Achieve Priority	Type of Resources Needed to Take Action	Funding Needed	In-Kind Resources Needed
Priority 3: Enhance survivor navigation services offered statewide			
Create a state level cancer survivor navigation coordinator position to help coordinate efforts and establish more community-based survivor navigation services through both health provider-based navigation (RN, NP, social work) and peer-based navigation (survivor to survivor)	Coordinator and survivor navigation salaries and benefits, development and maintenance of peer navigator program, travel costs for staff and volunteers	\$60,000 – 80,000 per full time equivalent (FTE); 4 FTEs needed	Recruitment of peer navigators
Develop training and certification programs for both types of survivor navigators (health providers and peer navigators)	Training and certification program development and ongoing maintenance	Approximately \$10,000	Training space
Define critical elements of survivor navigation	Partner involvement in defining critical elements of survivor navigation, dissemination of critical elements	NA	Partner time and involvement in defining critical elements of survivor navigation
Develop a clearinghouse for survivor navigation models, recognizing that there are different levels of navigation based on community resources/needs	Identification of survivorship navigation models appropriate for Alaska communities, website content development and promotion	Approximately \$20,000 for content development and adding to existing website or portal (see above)	Part-time staff to maintain website, promotion of website
Get support and acceptance of statewide survivor navigation efforts from existing health systems/hospitals	Partner and key stakeholder involvement in supporting statewide survivor navigation enhancement; share information about new Commission on Cancer standards for patient navigation	NA	Partner time and involvement in building support
Conduct evaluation of and document survivor navigation enhancements/outcomes	Add evaluation of survivor navigation enhancements to CCC evaluation component	NA	Partner involvement in designing evaluation

Actions to Achieve Priority	Type of Resources Needed to Take Action	Funding Needed	In-Kind Resources Needed
Priority 3: Enhance survivor navigation services offered statewide (CONTINUED)			
Advocate for policy changes to support survivor navigation including reimbursement for services and getting consent from patient for release of data at the beginning of cancer diagnosis	Analyze gaps in policies supportive of cancer survivor navigation (can be done through CCC program), identify specific policy changes needed, advocate for policy changes	NA	Partner involvement in analysis of and advocacy for policy change

Actions to Achieve Priority	Type of Resources Needed to Take Action	Funding Needed	In-Kind Resources Needed
Priority 4: Encourage the use of survivor care plans			
Identify elements of a survivor care plan that are culturally relevant for AK populations and how they can be included in survivor care plans	Review of existing survivor care plan elements, analysis and identification of unique elements relevant to AK	NA	Partner time and involvement in review of survivor care plans, identification of AK elements
Identify elements of a psychosocial care plan and how it can be used with a survivor care plan	Review of existing psychosocial care plan elements and development of recommendations for building into survivor care plans	NA	Partner time and involvement in review of psychosocial care plan elements
Educate providers and health systems about the need for survivor care plans/transition to primary care; incorporate how to deal with issues of completing survivor care plans into training	Development of training curriculum and materials, delivery of training	Approximately \$20,000 for training development and delivery	Travel costs for providers, training space, CME costs
Advocate for the use of treatment summaries among medical /radiation oncology providers, and that summaries be shared with patients and primary care providers	Development of messages about the need for treatment care summaries, identification of provider champions to assist with promotion, disseminate message to providers	NA	Partner time and involvement in developing and delivering messages about the need for treatment summaries

Actions to Achieve Priority	Type of Resources Needed to Take Action	Funding Needed	In-Kind Resources Needed
Priority 4: Encourage the use of survivor care plans (CONTINUED)			
Promote evidence-based survivor care plan templates	Add information about where to find and how to use survivor care plan templates to existing websites	NA	Partner staff support and time to identify existing resources to link to and to keep site up to date
Educate cancer survivors – both new survivors and longer-term survivors – about the importance of and need for survivor care plan; develop and distribute public service announcements about survivor care plans that feature survivors	Develop and distribute education materials, including public service announcements	Approximately \$50,000	Public service announcement sponsor
Create a checklist of critical pieces of information needed to complete a survivor care plan (for patients and providers)	Develop checklist for both patients and providers and build into existing survivor education efforts	NA	Partner time and involvement in developing checklist and incorporating into survivor education
Advocate for policies to support reimbursement of development of survivor care plans	Analyze gaps in policies to support reimbursement of survivor care plans (can be done through CCC program), identify specific policy changes needed, advocate for policy changes	NA	Partner involvement in analysis of and advocacy for policy change
Create templates and tools for cancer survivors to share with employers about their needs and potential return to work issues	Identify existing templates and tools, adapt templates and tools for use with existing survivor support programs, disseminate templates and tools	Approximately \$20,000 for a contractor to adapt and/or create templates and tools, dissemination plan	Partner involvement to assist in development

A Call to Action: What Can You Do to Help Meet the Needs of Alaska Cancer Survivors?

Now is the time for organizations and individuals to join the Alaska Comprehensive Cancer Partnership in meeting the needs of our survivors! Here are some ways you can help:

- If you are a **cancer survivor** encourage the organizations you volunteer for or are involved in to choose one or more of these cancer survivor priorities to work on and to consider providing in-kind support.
- If you are a **member of the Alaska Comprehensive Cancer Partnership** choose one or more of these cancer survivor priorities to work on and consider providing in-kind support.
- If you are a **foundation** you can talk to the Partnership about potential funding sources and how the Partnership can best request funding.
- If you are a **state legislator** you can use the resource plan as a basis for educating your peers about the need for survivorship programs and infrastructure in Alaska and their related costs.
- If you are a **hospital** you can use the resource plan to help guide your own cancer survivorship program planning and resource allocation decisions, to help extend the reach of your efforts.
- If you are a **health care provider** you can become a champion in educating other providers about the needs of cancer survivors and provide in-kind support and expertise to help achieve one or more of these priorities.

To find out more about how you can get involved or to offer assistance with a specific priority action(s) in this resource plan, contact:

Alaska State Comprehensive Cancer Control Program

Phone 907-269-8092

<http://dhss.alaska.gov/dph/Chronic/Pages/Cancer/comprehensive.aspx>

More Information about Strategies to Meet Cancer Survivor Needs

For more information about evidence-based cancer survivor programs, check out these resources:

- **A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies** –http://www.cdc.gov/cancer/survivorship/what_cdc_is_doing/action_plan.htm - Developed by CDC and LIVESTRONG to address the issues faced by the growing number of cancer survivors living with, through, and beyond cancer.
- **From Cancer Patient to Cancer Survivor: Lost in Transition, IOM report** –<http://iom.edu/Reports/2005/From-Cancer-Patient-to-Cancer-Survivor-Lost-in-Transition.aspx> - A report from the Institute of Medicine that outlines key actions to ensure the best outcomes for cancer patients, including the development and use of cancer survivor care plans.
- **Essential Elements of Survivorship Care: A LIVESTRONG Brief** – <http://www.livestrong.org/What-We-Do/Our-Approach/Reports-Findings/Essential-Elements-Brief> - Developed by LIVESTRONG with input from 150 key stakeholders, the essential elements of survivorship care that any effective cancer survivorship provider must provide (directly or via referral) to post-treatment cancer survivors. See page 8 of the Brief for a summary of the consensus elements.
- **Research-Tested Intervention Programs (RTIPs)** – <http://rtips.cancer.gov/rtips/index.do> - a searchable database of cancer control interventions and program materials designed to provide program planners and public health practitioners easy and immediate access to research-tested materials. Choose “survivorship” as a search term to see evidence-based interventions for survivors.

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- **Cancer Connection Alaska**
- **The J Michael Carroll Cancer Center at Fairbanks Memorial Hospital**
- **Leukemia Lymphoma Society**
- **LIVESTRONG**
- **Mind Matters Research LLC**
- **Providence Cancer Center, Patient Navigation Team**
- **State of Alaska, Breast and Cervical Health Check Program**
- **UAF Center for Alaska Native Health Research**



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