

# CANCER SURVIVORSHIP CARE PLANS: A TOOLKIT FOR HEALTH CARE PROFESSIONALS



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## An Introduction

### What is the California Dialogue on Cancer (CDOC)?

CDOC is a coalition of cancer control stakeholders from across the state. Stakeholders include state and local governments; private and nonprofit organizations; health, medical, and business communities; academic institutions; researchers; cancer survivors; caregivers; and advocates. The vision of CDOC is to reduce cancer suffering and mortality in California. CDOC was created specifically to develop and implement California's Comprehensive Cancer Control Plan.



### What is the CDOC Survivorship Care Plan Toolkit?

The CDOC Survivorship Care Plan Toolkit is a practical guide to advance the goal of increasing the awareness and understanding of survivorship care plans among systems of care, and to increase the utilization of survivorship care plans. The CDOC Survivorship Care Plan Advisory Group is a collaborative of cancer community stakeholders from across California, who have worked to develop this toolkit in partnership with Triage Cancer, to ultimately improve the quality of life of cancer survivors in California.

Triage Cancer is a national, nonprofit organization providing information and resources on the full spectrum of cancer survivorship issues to patients, survivors, caregivers, advocates, and healthcare professionals, through a national Speakers Bureau, educational events, and online tools, including an educational blog found at [www.TriageCancer.org/blog](http://www.TriageCancer.org/blog).



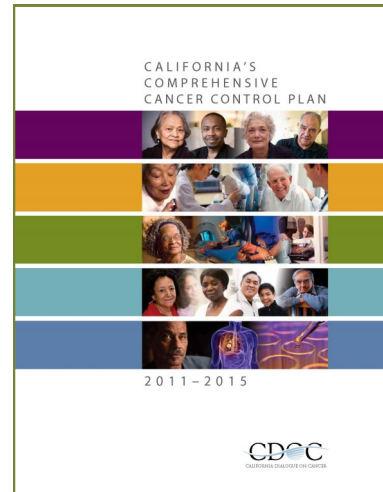
### What is Comprehensive Cancer Control?

The Centers for Disease Control and Prevention (CDC) defines Comprehensive Cancer Control 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.” The CDC created the National Comprehensive Cancer Control Program (NCCCP) to help states, tribes, and territories form coalitions to conduct comprehensive cancer control. The California Department of Public Health received funding from the CDC in 2002 to establish California's Comprehensive Cancer Control Program and the CDOC coalition.



## What is California's Cancer Control Plan?

California's Comprehensive Cancer Control Plan (the Plan) is a strategic plan to reduce the cancer burden in our state. It provides guidance to stakeholders on a wide range of health and social disciplines that can play a role in controlling cancer, including primary prevention, early detection and screening, treatment, survivorship, quality of life and end-of-life care, as well as such cross-cutting issues as advocacy, eliminating disparities, research, and surveillance. The Plan's strategies are intended to direct collective efforts toward specific and measurable objectives that will reduce the cancer burden.



## What is Cancer Survivorship?

As of January 1, 2014, there are more than 14.5 million cancer survivors in the United States. Improvements in early detection and treatment have resulted in more people surviving longer after being diagnosed with cancer. The National Cancer Institute considers an individual a survivor from the time of diagnosis throughout life.

After the diagnosis and treatment of cancer, survivors and their families must still contend with a host of physical, psychological, and socioeconomic issues. A cancer survivorship care plan is a document that includes a treatment summary, recommendations for follow up and psychosocial care, and other information to enable survivors to anticipate and address the long-term and late-term effects of treatment. Although a cancer survivorship care plan can be used at any point during care, it is most common for patients to receive a plan when they complete treatment. Survivorship care plans can also be helpful for some patients who are receiving long-term treatment.

California's 2011-2015 Comprehensive Cancer Control Plan included the following goal related to cancer survivorship: *To improve California cancer survivors' quality of life through increased awareness, education, and access to survivorship resources and services.*

An identified strategy to meet this goal is to increase the number of cancer survivors who receive a survivorship care plan, by educating healthcare professionals regarding the importance of integrating survivorship care plans into standard practice; promoting the availability of survivorship care plans to cancer survivors; and promoting systems change to integrate survivorship care plans into systems of care.

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# An Introduction to Cancer Survivorship & Survivorship Care Plans

Improvements in early detection and treatment have resulted in more people surviving longer after being diagnosed with cancer. The National Cancer Institute (NCI) considers an individual a cancer survivor from the time of diagnosis throughout life. The National Coalition for Cancer Survivorship also adopts this definition, while the Institute of Medicine (IOM) defines a cancer survivor as one who has completed treatment for their initial cancer. The Association of Community Cancer Centers defines cancer survivorship as “the experience of living with, through and beyond cancer for both patients and the people in their lives who are impacted by the diagnosis.” Cancer survivors may each have their own definition of what cancer survivorship means to them; however, for the purposes of this toolkit, we adopt the NCI definition of cancer survivorship beginning at diagnosis.

As of January 1, 2014, there are more than 14 million cancer survivors in the United States.<sup>i</sup> In



the 1930’s, less than one out of five cancer patients were alive five years after treatment. Today, more than three out of five cancer patients will be alive five years after diagnosis and treatment.<sup>ii</sup> This improvement in cancer survivorship can be attributed to improvements in early detection and treatment, which have resulted in more people surviving longer after being diagnosed with cancer. There are also those who live for extended periods of time with cancer as a chronic or advanced disease, on long-term therapy with alternating periods of remission and relapse.

Although the numbers of cancer survivors have increased, after the diagnosis and treatment of cancer, survivors and their families must still contend with a host of physical, psychological, practical, and financial issues.

In 2004, the Centers for Disease Control and Prevention (CDC) and the Lance Armstrong Foundation (now known as LIVESTRONG™ Foundation) released “A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies.”<sup>iii</sup> This action plan suggested that a public health effort could help to effectively support cancer survivors by:

- Preventing secondary cancers and the recurrence of cancer whenever possible.
- Promoting appropriate management following diagnosis and/or treatment to ensure the maximum number of years of healthy life for cancer survivors.
- Minimizing preventable pain, disability, and psychosocial distress for those living with, through, and beyond cancer.



- Supporting cancer survivors in accessing the resources and the family, peer, and community support they need to cope with their disease.

Then, in 2005, the IOM formed a committee to examine the range of medical and psychosocial issues faced by cancer survivors and to make recommendations to improve their health care and quality of life. The committee's findings were published in a report called, "Lost in Transition: From Cancer Patient to Cancer Survivor."<sup>iv</sup> One of the recommendations of the report was that after completing their primary treatment, patients should be provided with a comprehensive care summary and follow-up plan. Such a document would be called a "Survivorship Care Plan." The report called out five specific categories of information that should be included in each survivorship care plan:

- Cancer type, treatments received, and their potential consequences;
- Specific information about the timing and content of recommended follow-up;
- Recommendations regarding preventive practices and how to maintain health and well-being;
- Information on legal protections regarding employment and access to health insurance; and
- The availability of psychosocial services in the community.<sup>v</sup>

The IOM went on to say that the survivorship care plan should be written by the providers who coordinated the patient's oncology treatment and that the survivorship care plan should then be explained to the patient. The report acknowledged that the process of providing a survivorship care plan is not currently paid for by health insurers, but suggested that it should be.

To encourage the adoption of survivorship care plans, the IOM released a series of fact sheets for health care professionals and cancer survivors, found here: <http://iom.nationalacademies.org/Reports/2005/From-Cancer-Patient-to-Cancer-Survivor-Lost-in-Transition>.

### **Elements of an Effective Survivorship Care Plan**

An effective cancer survivorship care plan is a document that includes a summary of a patient's treatment, recommendations for follow-up care, and other relevant information to help survivors anticipate and address the long-term and late-term physical, psychosocial, practical, and financial effects of cancer treatment. Another benefit of cancer survivorship care plans is to assist in the coordination and transition of a survivor's care from an oncology setting to a primary care setting as oncology treatment is completed as well as transition to care providers when a patient relocates. Survivorship care plans can also assist when a survivor transitions from a pediatric to an adult health care team.

Although a cancer survivorship care plan can be used at any point during care, it is most common for survivors to receive a plan when they complete treatment. Survivorship care plans can also be helpful for some survivors who are receiving long-term treatment. Survivors should be encouraged to provide a copy of their care plan to their primary care providers and other health care providers throughout their life.

Every cancer survivorship care plan should include comprehensive clinical and non-clinical information to be the most effective in assisting survivors in navigating through the variety of cancer survivorship issues that may arise. Plans should include an introduction that describes to survivors what the document is and how it can help them. Plans may also include an introduction for future health care providers.

**Elements of an effective survivorship care plan:<sup>vi</sup>**

- Details of the cancer diagnosis
  - Date
  - Type of cancer
  - Location
  - Stage
  - Histology
- Names and contact information of the health care providers and treatment facilities
- Treatments administered
  - Chemotherapy/biotherapy – regimen, drug, dose, cycles, cumulative amount, any clinical trial information
  - Radiation – type, dose, site
  - Surgery – procedure
- Follow-up care plan
- Specific recommendations for ongoing care
  - Scheduling of future visits with an oncology specialist
  - Surveillance testing for recurrence
  - Identifying and managing long-term and late-term effects
- Health promotion strategies
  - Smoking cessation and alcohol restrictions
  - Nutrition and dietary modifications
  - Regular physical activity and weight-bearing exercise
  - Chemoprevention strategies for secondary prevention
  - Immunizations



- Psychosocial issues
  - Effects on relationships
  - Sexual functioning
  - Parenting
  - Genetic counseling
  - Spirituality
- Practical issues
  - Insurance
  - Employment
  - Education
  - Other legal issues
  - Financial impact of cancer
- Listing of cancer-related resources and information for survivors



In 2010, a LIVESTRONG™ survey found that 98 percent of cancer survivors surveyed experienced a wide array of physical, emotional, and practical issues after a cancer diagnosis. However, only 58 percent of cancer survivors who experience emotional concerns received help and only 20 percent of those with practical concerns received help.<sup>vii</sup> Cancer survivorship care plans can play a valuable role in providing guidance on where cancer survivors can receive help with these emotional and practical concerns, in addition to providing a treatment summary and follow-up care plan.

## Survivorship & Survivorship Care Plan Guidelines

As the number of cancer survivors has grown, there has been increased research and attention paid to the challenges facing cancer survivors. Various cancer community stakeholders have developed cancer survivorship guidelines. For example, the American Society of Clinical Oncology (ASCO) has released guidelines on clinical care for certain types of cancer as well as issues such as fertility, neuropathy, and palliative care. ASCO has also published guidelines with the American Cancer Society on breast cancer survivorship.<sup>viii</sup>

The National Comprehensive Cancer Network (NCCN) has also developed cancer survivorship guidelines.<sup>ix</sup> NCCN, a not-for-profit alliance of the world's leading cancer centers, promotes the importance of continuous quality improvement and recognizes the value of creating clinical practice guidelines appropriate for use by patients, clinicians, and other healthcare decision

makers. The NCCN Guidelines<sup>®</sup> are a comprehensive set of guidelines detailing the sequential management decisions and interventions of individuals involved in cancer care—including physicians, nurses, pharmacists, payers, patients and their families—with the ultimate goal of advancing patient care in the fight against cancer.

NCCN Guidelines<sup>®</sup> for cancer survivorship were released in 2013 and include late effects/long-term psychosocial and physical problems (i.e., anthracycline-induced cardiac toxicity, anxiety and depression, cognitive function, fatigue, pain, sexual function, and sleep disorders) as well as preventive health (i.e., physical activity, nutrition, weight management, supplement use, and immunizations and infection).<sup>x</sup> As the NCCN Guidelines<sup>®</sup> recommend ongoing assessment of a survivor’s needs on a routine basis, NCCN also offers a sample assessment tool with two to three questions on each of the key topics included in the guidelines.

There are also cancer survivorship guidelines that are available for specific types of cancers, as well as for specific age groups. For example, the Children’s Oncology Group (COG) released Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers.<sup>xi</sup> These guidelines include physical, psychosocial, and practical issues facing these age groups.

To further support cancer survivors, some have suggested that a health care facility’s use of cancer survivorship care plans should be a factor in the accreditation of that facility. To that end, in 2012, the Commission on Cancer (CoC), a program of the American College of Surgeons (ACoS), released a new standard focused on the delivery of survivorship care plans in “Cancer Program Standards 2012: Ensuring Patient-Centered Care.”<sup>xii</sup> The CoC is a multidisciplinary accreditation program that evaluates cancer programs according to comprehensive, patient-centered standards. “More than 1,500 CoC-accredited cancer programs across the United States and Puerto Rico treat nearly 70 percent of recently diagnosed cancer patients each year.”<sup>xiii</sup>



The accreditation standard on survivorship care plans reads as follows:

*“STANDARD 3.3 Survivorship Care Plan*

*The cancer committee develops and implements a process to disseminate a treatment summary and follow-up plan to patients who have completed cancer treatment. The process is monitored and evaluated annually by the cancer committee.*

**DEFINITION AND REQUIREMENTS**

*The Institute of Medicine report From Cancer Patient to Cancer Survivor outlines the importance of providing cancer survivors with a comprehensive treatment summary and follow-up plan (i.e. survivorship care plan) that reflects the treatment they received, and addresses post-treatment needs and follow-up care to improve health and quality of life.*

*The Survivorship Care Plan (SCP) is a record that summarizes and communicates what transpired during active cancer treatment, recommendations for follow-up care and surveillance testing/ examinations, referrals for support services the patient may need going forward and other information pertinent to the survivor’s short- and long-term survivorship care.*

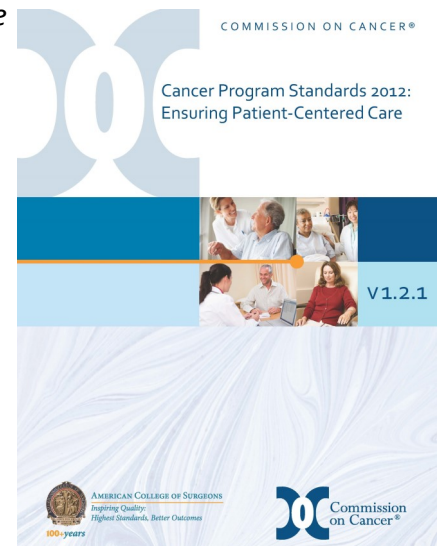
*The American Society of Clinical Oncology (ASCO) has defined the minimum data elements to be included in a treatment summary and SCP. This core set of data elements and templates are available on the ASCO website. At a minimum, all SCPs must include ASCO’s recommended elements describing treatment summary and a follow-up care plan to meet compliance for this standard. Additional resources to assist with the development of SCPs are available through the National Coalition for Cancer Survivorship, Journey Forward, American Cancer Society, and LIVESTRONG Foundation.*

**PROCESS REQUIREMENTS**

*Cancer programs must develop and implement processes to monitor the formation and dissemination of a SCP for analytic cases with Stage I, II, or III cancers that are treated with curative intent for initial cancer occurrence and who have completed active therapy.*

*Within the SCP processes are policies and procedures identifying the appropriate healthcare provider(s) from patients’ oncology care team who will be responsible for approving and discussing the SCP. Providers who are part of the patient’s care team that are appropriate under the standard to deliver the SCP include:*

- *Physicians*
- *Registered Nurses*
- *Advanced Practice Nurses*
- *Nurse Practitioners*
- *Physician Assistants*
- *Credentialed clinical navigators (does not include lay navigator)*



*The printed or electronic survivorship care plan must contain input from the principal physician and oncology care team who coordinated the oncology treatment for the patient, as well as input from the patient's other care providers (outside treatment information), if applicable. If two separate facilities are providing treatment, both facilities collaborate to complete and provide the SCP. In all cases, programs, hospitals, and physician offices should work together to provide the information necessary for completion of a SCP that contains all required elements.*

*The survivorship care plan is given and discussed with the patient upon completion of active, curative treatment and recorded in the patient medical record. The timing of delivery of the SCP is within one year of the diagnosis of cancer and no later than six months after completion of adjuvant therapy (other than long-term hormonal therapy). The 'one year from diagnosis' requirement to have a SCP delivered is extended to 18-months for patients receiving long-term hormonal therapy. Providing the SCP by mail, electronically, or through a patient portal without discussion with the patient does not meet the standard.*

*Patients excluded (ineligible) from Standard 3.3 requirement include:*

- Patients with Stage 0 or IV or metastatic disease, though survivors by varying definitions are not required to receive a SCP under Standard 3.3. However, programs may choose to provide SCPs to metastatic patients.*
- Patients who are pathologically diagnosed but never treated or seen for follow-up by the accredited program are not required to receive a SCP from the facility providing diagnosis."*

Standard 3.3 was supposed to be phased in by 2015, in order for cancer programs to receive CoC accreditation. However, in late 2013, the CoC conducted a survey of cancer programs on their readiness to implement this standard and found that only 37 percent of programs felt "completely confident" they could implement Standard 3.3 by 2015.<sup>xiv</sup> In order to assist cancer programs with implementation, the CoC has revised the timeline for the use of survivorship care plans.

Implementation of the standard must follow the schedule as outlined:

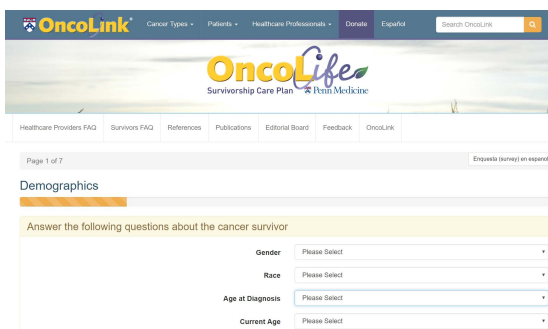
- January 1, 2015–December 31, 2015: Provide SCPs to ≥ 10 percent of eligible patients who have completed treatment.
- End of 2016: Provide SCPs to ≥ 25 percent of eligible patients who have completed treatment.
- End of 2017: Provide SCPs to ≥ 50 percent of eligible patients who have completed treatment.
- End of 2018: Provide SCPs to ≥ 75 percent of eligible patients who have completed treatment.

The CoC also narrowed the data elements that are to be included in survivorship care plans, to simplify the process for survivorship care plan implementation, focusing only on a treatment summary, follow up care plan, a list of items (e.g., emotional or mental health, parenting, work/employment, financial issues, and insurance) "in standard language" stating that survivors with these issues should speak with his or her oncologist and/or primary care physician, and a list of local and national resources for the patient.<sup>xv</sup>



## Survivorship Care Plan Templates

Because survivorship care plans have not been readily available within cancer programs, to date, there are a few survivorship care plan templates that patients can use to develop a plan for themselves, with the use of their medical records. As medical records are often hard to decipher for patients, engaging a member of the health care team to assist in the completion of the survivorship care plan is often necessary. Health care institutions may be considering reviewing these plans in developing their own survivorship care plan templates. Examples of these do-it-yourself plans include:



OncoLink

OncoLife  
Survivorship Care Plan Penn Medicine

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Demographics

Answer the following questions about the cancer survivor

Gender: Please Select

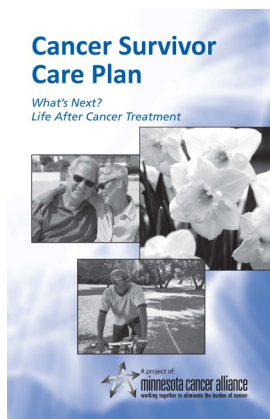
Race: Please Select

Age at Diagnosis: Please Select

Current Age: Please Select

### OncoLife Survivorship Care Plan - Penn Medicine's

**OncoLink:** This online tool requires survivors to complete a brief questionnaire and then compiles a survivorship care plan for survivors to review and discuss with their health care team, including both oncology and primary care. Health care professionals can also use this tool on behalf of their patients. [www.oncolink.org/oncolife](http://www.oncolink.org/oncolife)



**What's Next? Life After Cancer Treatment:** This survivorship care plan template developed by the Minnesota Cancer Alliance, is written in lay language and helps patients to keep track of cancer treatment, manage follow-up care, gain an awareness of side effects, have a dialogue with members of their health care team, and access resources to address physical, emotional, and practical issues. [http://mncanceralliance.org/wp-content/uploads/2013/07/SurvivorCarePlan3202012\\_Final.pdf](http://mncanceralliance.org/wp-content/uploads/2013/07/SurvivorCarePlan3202012_Final.pdf)



**Journey Forward My Care Plan:** This template is for patients to start their own survivorship care plan and to complete it with the help of their health care team. The template is available as a free mobile app (iOS and Android) and as a printable PDF form.

[www.journeyforward.org/planning-tools/my-care-plan](http://www.journeyforward.org/planning-tools/my-care-plan)

There are also a number of survivorship care plan templates available for health care professionals to complete on behalf of their patients. Some are documents that can be filled in and printed out, while some are online tools to enter in information and create a survivorship care plan. Some of the most common templates for survivorship care plans include:

### Journey Forward Survivorship Care Plan

**Builder:** This online tool, created through a collaboration of the UCLA Cancer Survivorship Center, the National Coalition of Cancer Survivorship, Wellpoint, and Genentech, is for health care professionals to use to complete a survivorship care plan for their patients. This online tool is fully customizable and is in line with the CoC Standard on survivorship care plans.

[www.journeyforward.org](http://www.journeyforward.org)

**American Society of Clinical Oncology (ASCO) Cancer Treatment Plan and Summary.**<sup>xvi</sup> In addition to the cancer survivorship guidelines, ASCO has developed a cancer survivorship care plan for use by cancer programs. This template meets the CoC Standard for survivorship care plans and is for all types of cancer: <http://www.asco.org/practice-research/survivorship-care-clinical-tools-and-resources>.

ASCO has also developed survivorship care plan templates for patients with different types of cancer:

- Breast Cancer: [www.asco.org/sites/www.asco.org/files/asco\\_scp\\_template\\_breast\\_final.docx](http://www.asco.org/sites/www.asco.org/files/asco_scp_template_breast_final.docx)
- Colorectal Cancer: [www.asco.org/sites/www.asco.org/files/asco\\_scp\\_template\\_crc\\_final.docx](http://www.asco.org/sites/www.asco.org/files/asco_scp_template_crc_final.docx)
- Non-Small Cell Lung Cancer: [www.asco.org/sites/www.asco.org/files/asco\\_scp\\_template\\_nslc\\_final.docx](http://www.asco.org/sites/www.asco.org/files/asco_scp_template_nslc_final.docx)
- Small Cell Lung Cancer: [www.asco.org/sites/www.asco.org/files/asco\\_scp\\_template\\_sclc\\_final.docx](http://www.asco.org/sites/www.asco.org/files/asco_scp_template_sclc_final.docx)
- Prostate Cancer: [www.asco.org/sites/www.asco.org/files/asco\\_scp\\_template\\_postate\\_final.docx](http://www.asco.org/sites/www.asco.org/files/asco_scp_template_postate_final.docx)
- Diffuse Large B-Cell Lymphoma: [www.asco.org/sites/www.asco.org/files/asco\\_scp\\_template\\_dlbcl\\_final.docx](http://www.asco.org/sites/www.asco.org/files/asco_scp_template_dlbcl_final.docx)

**Did you know?** The American College of Surgeons' Commission on Cancer mandated the implementation of the survivorship care plan by 2015. A survivorship care plan may improve survival and reduce morbidity via coordinated clinical care informed by documenting and following surveillance care and recommended tests, late effects and symptom management, and healthy lifestyle promotion.

*African-American women have a five year survival rate of 78 percent after diagnosis as compared to 90 percent for white women. Early detection, appropriate treatment, post-treatment tests and follow-up care save lives.*



*African Americans are 25 to 40 percent more likely to either be diagnosed at younger ages, have more aggressive and fast growing, triple negative and inflammatory breast cancers and other major chronic illness, hence a survivorship care plan is a crucial guide to their care.*

After being diagnosed with breast cancer, many experience some fear and anxiety and may worry about what to do to gain the best outcomes through the phases of treatments, after active treatment ends and during the next stages of life. Most breast cancer survivors recover to normal well-being and functioning within one to two years. The survivorship care plan is your roadmap to follow-up care and well-being.

**A survivorship care plan answers three main questions:**

- What treatments are most effective for me and what are the possible side effects?
- What follow-up care do I need from my oncology and primary care team?
- What actions and behaviors should I practice to improve my health and well-being?



Some cancer programs have developed customized survivorship care plans for their patients,<sup>xvii</sup> while others have incorporated the survivorship care plan process into their electronic medical record system (i.e., Cerner, Epic, OncoNav, etc.), which can, in particular, facilitate the creation of the treatment summary section of the survivorship care plan.

### Survivorship Care Plans for Specific Populations

Furthermore, research has indicated that providing survivorship care plans that are culturally, linguistically, and age appropriate to patients is incredibly important; however, there are limited examples of such survivorship care plan templates available.<sup>xviii</sup>

- OncoLife Survivorship Care Plan - Penn Medicine's OncoLink:** This online tool is also available in Spanish. <http://es.oncolink.org/oncolife>
- City of Hope Latina Breast Cancer Survivorship Care Plan (English/Spanish):** [www.cityofhope.org/document/latina-spanish-hopeful-living](http://www.cityofhope.org/document/latina-spanish-hopeful-living)
- City of Hope Young Breast Cancer Survivorship Care Plan (English/Spanish):** [www.cityofhope.org/document/young-breast-cancer-survivorship-care-plan](http://www.cityofhope.org/document/young-breast-cancer-survivorship-care-plan)
- City of Hope African American Breast Cancer Survivorship Care Plan:** [www.cityofhope.org/document/african-american-scp-8-2014](http://www.cityofhope.org/document/african-american-scp-8-2014)
- Passport for Care®:** This online tool, for childhood cancer survivors and their healthcare providers, was developed by Texas Children's Cancer Center and The Center for Collaborative and Interactive Technologies at Baylor College of Medicine in collaboration with the COG. It is currently in use in more than 125 clinics for approximately 20,000 survivors, and is available at no cost to COG member institutions and other providers of care to childhood cancer survivors. The Passport for Care is the electronic version of the COG's Cancer Treatment Summary and Long-Term Follow-Up Guidelines. <http://txch.org/cancer-center/long-term-survivor-program/passport-for-care>



Las buenas noticias para la sobrevivencia del cáncer son que los números están creciendo, con un estimado 14 millones de sobrevivientes viviendo en los Estados Unidos hoy día. Desafortunadamente, los tratamientos del cáncer no son sin consecuencias y estos sobrevivientes están lidiando con efectos a plazo largo de los tratamientos con poca dirección. El Instituto de Medicina (IOM, por sus siglas en inglés) investigó el estado de cuidado para los sobrevivientes de cáncer y encontró que había poca dirección disponible para los sobrevivientes y sus proveedores de cuidado médico para superar los problemas médicos y sicosociales que pueden presentarse después del tratamiento. El IOM sugiere que una vez que una persona haya terminado la terapia de cáncer, se le debe proporcionar un resumen de los tratamientos recibidos y un "plan de cuidado" de seguimiento. Este plan de cuidado debe resumir los efectos tardíos potenciales, sus síntomas y sus tratamientos, recomendaciones para la detección temprana del cáncer, efectos sicosociales, opciones eficaces sobre la prevención, referidos para el cuidado de seguimiento y una lista de recursos de apoyo. Aunque este plan es extremadamente importante, la cantidad de tiempo que requeriría no sería posible para la mayoría de las prácticas de oncología.

Plan de Atención Oncolife en Inglés

**Empieza**

Este programa gratuito y fácil de usar proporciona sobrevivientes de cáncer con información sobre los riesgos de salud que enfrentan como consecuencia de terapias contra el cáncer

[Desarrollar Mi Plan de Atención](#)



**Did You Know?** The American College of Surgeons' Commission on Cancer mandated the implementation of the survivorship care plan by 2015. A survivorship care plan may improve survival and reduce morbidity via coordinated clinical care informed by documenting and following surveillance care and recommended tests, late effects and symptom management, and healthy lifestyle promotion.

**¿Sabía Usted?** La Comisión de Cáncer del Colegio Americano de Cirujanos ha ordenado la implementación de un plan de cuidado de sobrevivencia para el año 2015. Un plan de sobrevivencia puede mejorar la sobrevivencia y reducir la morbilidad mediante el cuidado clínico coordinado y la documentación de un plan de vigilancia y pruebas recomendadas así como el manejo de síntomas y la promoción de prácticas de una vida saludable.

Breast cancer is the most commonly diagnosed cancer and the second leading cause of cancer death among Latinas in the United States. Latinas are diagnosed at a younger age, advanced stages, have larger tumors, lower breast survival rates, and are at somewhat greater risk of BRCA mutations.<sup>1,2</sup> Latinas report delays in diagnosis and receipt of care and greater distress due to breast cancer.<sup>3,4</sup>

El cáncer de mama es el cáncer más comúnmente diagnosticado y la segunda causa de muerte por cáncer entre las mujeres en los Estados Unidos. Las latinas son diagnosticadas a una edad más joven, en etapas avanzadas, tienen tumores más grandes, tienen niveles de supervivencia más bajos<sup>1,2</sup> y tienen un riesgo más alto de mutaciones de BRCA.<sup>1,2</sup> Las latinas han reportado retrasos en el diagnóstico y el acceso a los servicios de salud y un mayor nivel de angustia por el cáncer de mama.<sup>3,4</sup>

**After being diagnosed with breast cancer, many experience some fear and anxiety and may worry about what to do to gain the best outcome through the phases of treatment, after active treatment ends and during the next stages of life. Most breast cancer survivors receive no formal self-care and functioning within one to two years. The survivorship care plan is your roadmap to follow-up care and well-being.**

**A survivorship care plan answers three main questions:**

- What treatments are most effective for me and what are the possible side effects?
- What follow-up care do I need from my oncology and primary care team?
- What actions and behaviors should I practice to improve my health and well-being?

**Después de ser diagnosticada con cáncer de mama, muchas experimentan un poco de miedo y ansiedad, y se pueden preocupar sobre qué hacer para tener los mejores resultados a través de las fases del tratamiento, después de finalizar el tratamiento activo y durante las próximas etapas de la vida. La mayoría de los sobrevivientes de cáncer de mama no reciben un plan de bienestar y el funcionamiento normal dentro de 1 a 2 años. El plan de cuidado de sobrevivencia es un mapa para el cuidado de seguimiento y el bienestar.**

**El plan de cuidado de sobrevivencia responde a tres preguntas principales:**

- ¿Qué tratamientos son más efectivos para mí y cuáles son los efectos secundarios posibles?
- ¿Qué cuidados de seguimiento necesito de mi oncólogo y equipo de cuidado médico primario?
- ¿Qué acciones y comportamientos debo practicar para mejorar la salud y el bienestar?

## Implementing Survivorship Care Programs

This toolkit is intended to be a resource for health care professionals to increase their understanding of survivorship care plans and to encourage health care professionals to incorporate survivorship care plans into their survivorship care programs. While many cancer programs are pursuing the implementation of cancer survivorship care plans to comply with the CoC standard, there are some cancer programs that are not CoC accredited, but may be weighing the use of survivorship care plans. There are a number of resources available to support the implementation of a cancer survivorship program, and, more specifically, the use of cancer survivorship care plans.

For example, the George Washington Cancer Institute (GWCI) has a “Guide for Delivering Quality Cancer Survivorship Care”<sup>xxix</sup> and the Association of Community Cancer Centers provides a section on their website called: “Cancer Survivorship Tools & Resources for the Multidisciplinary Team,” which includes cancer survivorship program implementation case studies.<sup>xx</sup> The Advisory Board Company provides a grid to assist in assessing how to start or grow cancer survivorship programs.<sup>xxi</sup> The grid shows how a cancer program can move from the status quo, to a basic survivorship program, to an advanced survivorship program.

<b>Status Quo: Patient Education</b>	<b>Basic Survivorship Program: Patient Education</b>	<b>Advanced Survivorship Program: Patient Education</b>
<ul style="list-style-type: none"> <li>Survivorship pamphlets given to patients</li> </ul>	<ul style="list-style-type: none"> <li>Survivorship information provided during pre-treatment education</li> </ul>	<ul style="list-style-type: none"> <li>Clinicians introduce survivorship early, revisit regularly during treatment</li> </ul>
<ul style="list-style-type: none"> <li>Survivorship information included on website</li> </ul>	<ul style="list-style-type: none"> <li>Cancer program staff member reintroduces survivorship at conclusion of active treatment</li> </ul>	<ul style="list-style-type: none"> <li>Survivorship conversations include discussion of reconnection to primary care</li> </ul>

The details of incorporating a process to use survivorship care plans within a larger cancer survivorship program will likely be specific to each cancer program; however, most programs will need to answer some basic questions before moving forward. Memorial Sloan Kettering Cancer Center provides survivorship resources for health care professionals, including a list of questions that should be considered before implementing a survivorship care plan process, such as:<sup>xxii</sup>

- *What resources will be needed (i.e., personnel, technology, supplies, etc.)?*
- *How will the treatment data be collected and from where?*
- *Who will be responsible for collecting and entering the data?*
- *What services will be included in follow-up care?*

- *What guidelines will be followed for surveillance?*
- *Will the care plan cover all types of cancer or be tumor-site specific?*
- *Will the care plan be culturally, linguistically, and age specific?*
- *When is the most appropriate time to review the survivorship care plan with patients –at the end of treatment, sometime before, or sometime later?*
- *Should there be a formal transition visit?*
- *Who will receive the care plan?*
- *Will the care plan be stored electronically?*
- *Will the care plan be updated periodically? Who will be responsible for the update and what will trigger the update?*
- *How does the care plan get shared with the primary care team?*



These basic questions highlight the systematic changes that may need to take place to implement an effective survivorship care plan process. Some cancer programs have created the position of survivorship navigator to coordinate the delivery of survivorship care plans and other survivorship care; however, many cancer programs are relying on existing staff to provide survivorship care plans.

Cancer centers in academic settings often use one of two models for the delivery of survivorship care and survivorship care plans: a consultative model or a longitudinal model.<sup>xxiii</sup> In a consultative model:

- An oncologist refers the survivor for a survivorship evaluation appointment or a survivor can self-refer.
- Before the appointment, a health care provider completes a survivorship care plan for the survivor.
- During the appointment, a health care provider evaluates the survivor, shares the care plan with the survivor, and provides any necessary referrals and resources.
- After the appointment, a copy of the care plan and the evaluation are sent to the referring oncologist and the primary care physician. The oncologist continues the long-term follow-up care of the survivor for some period of time.

In a longitudinal model, survivors are transitioned from their oncologist to a survivorship clinic within a period of up to five years after treatment. Survivors are then followed by the survivorship clinic for a pre-determined period of time, before being transitioned to a primary care provider.

For survivors of childhood cancer, other models of care can be considered, and are described in the COG's Long-Term Follow-Up Program Resource Guide, here: [www-survivorshipguidelines.org/pdf/LTFUResourceGuide.pdf](http://www-survivorshipguidelines.org/pdf/LTFUResourceGuide.pdf).

To assist cancer programs in navigating these issues and options, the next two sections of the toolkit focus on the implementation challenges and best practices that have been uncovered by cancer programs already using survivorship care plans.



## Survivorship Care Plan Implementation Challenges

There are two categories of challenges related to a cancer program's implementation of survivorship care plans: 1) barriers to providing care plans, and 2) issues with the approach to care plans.<sup>xxiv</sup>

### ***Barriers to providing survivorship care plans***

Barriers to providing survivorship care plans include a lack of awareness about the need for care plans and the availability of care plan resources on the part of the survivor, the oncology health care team, and primary care physicians. For example, primary care providers have reported that additional training is needed to provide information on cancer treatment, survivorship care, and coordinated care.<sup>xxv, xxvi</sup>

Research has also indicated that there are also some very practical challenges to the delivery of survivorship care plans, including a lack of time for health care teams to complete care plans, a lack of technology and resources for cancer programs to provide care plans, and a lack of reimbursement for the time health care teams spend completing and delivering survivorship care plans.<sup>xxvii</sup> A 2013 assessment of cancer programs to determine their readiness to implement the CoC standard on survivorship care plans found that the most common stated barriers to implementation were "not enough staff" (78 percent), "time" (86 percent), and "financial" (75 percent).<sup>xxviii</sup>

Research studies on the delivery of care plans have indicated that just compiling the data for the treatment summary component of a survivorship care plan can take hours.<sup>xxix</sup> A study using the Journey Forward platform to deliver a survivorship care plan to colon cancer patients found that, on average, it took 49 minutes to complete a survivorship care plan for a survivor who had surgery

and 90 minutes for a survivor who received both surgery and chemotherapy.

One option to reduce the time spent on providing survivorship care plans is to use a simplified survivorship care plan template. To address the time concern, in the fall of 2014, ASCO released a revised survivorship care plan template, which, when studied, was found to only take approximately 30 minutes to complete.<sup>xxx</sup>

Another option to address this challenge would be to increase the use of technology to complete survivorship care plans; however, not every oncology provider uses electronic medical records (EMR) and most EMR platforms do not have the ability to automatically pull the needed information for a survivorship care plan's treatment summary. There are some EMR platforms which exist that have some of this capability, but most cancer programs will not be willing to transition their entire EMR system to a new platform just to make it easier to provide a cancer survivorship care plan.<sup>xxxii</sup> Oncology health care providers can work with their existing EMR providers to investigate how to customize this functionality.

Another barrier to cancer program adoption of survivorship care plans is the lack of specific reimbursement for the time health care providers spend completing and delivering survivorship care plans.<sup>xxxiii</sup> However, Journey Forward provides a few suggestions for billing the time spent examining or counseling a survivor. For instance, regular office visit evaluation and management CPT codes may be used for visits during which a patient is educated about their personal cancer treatment history, the appropriate surveillance for recurrence or second primary cancers, and the risks of late or long-term side effects. The determination of whether there is a procedure billing code that can be used will depend on the services performed.<sup>xxxiv</sup> It is always important to check each survivor's health insurance policy before billing, to ensure coverage. For examples of medical codes visit, [http://www.accc-cancer.org/oncology\\_issues/articles/MJ13/MJ13-Billing-Challenges-for-Survivorship-Services.pdf](http://www.accc-cancer.org/oncology_issues/articles/MJ13/MJ13-Billing-Challenges-for-Survivorship-Services.pdf)

### ***Issues with the approach to survivorship care plans***

Issues with the approach to survivorship care plans include: a lack of consensus about the data elements that should be included in a survivorship care plan; an absence of agreement on the details of a survivorship care plan delivery process; confusion about who is responsible for a survivor's follow-up care; and a dearth of research demonstrating the impact of survivorship care plans on survivorship outcomes.

## BARRIERS TO PROVIDING CARE PLANS

- ◇ Lack of awareness of the need for survivorship care plans on the part of the survivor and the health care team
- ◇ Lack of awareness of the availability of survivorship care plan resources on the part of the survivor and the health care team
- ◇ Lack of time for health care teams to complete survivorship care plans for survivors
- ◇ Lack of technology and resources for health care teams to complete survivorship care plans for survivors
- ◇ Lack of reimbursement for the time health care teams spend completing survivorship care plans for survivors

A lack of consensus about which data elements should be included in a survivorship care plan has been cited as a factor in the lack of provision of survivorship care plans.<sup>xxxv,xxxvi</sup> As discussed above, there are a number of survivorship care plan templates available for use and some cancer programs have chosen to further customize their own version of a survivorship care plan. While

## ISSUES WITH THE APPROACH TO CARE PLANS

- ◇ Lack of consensus about survivorship care plan implementation. There is no clear evidence as to:
  - ◇ The appropriate timing on when to deliver a care plan to a survivor
  - ◇ The data elements included in a care plan
  - ◇ The process for delivery of a care plan
  - ◇ How the care plan is shared with a primary care physician and who is responsible for a survivor's follow up care
- ◇ Lack of adequate research demonstrating the value of survivorship care plans

the IOM clearly laid out the essential elements of a cancer survivorship care plan, the more comprehensive templates have shown to be burdensome to complete.<sup>xxxvii</sup> Additionally, some cancer programs have adopted plans that focus on documenting the clinical details of past treatment and fail to provide adequate information on appropriate follow-up care and/or psychosocial and practical issues. In a review of studies on the use of cancer survivorship care plans, while providers expressed a preference for a streamlined version that clearly identified which components of care were their responsibility, survivors wanted more content on health promotion, psychosocial support, and financial and other resources.<sup>xxxviii</sup>

There is also an absence of agreement about the most effective process for delivery of a care plan, including which survivorship care plan template will be used, which members of the health care team will participate in the creation and delivery of the survivorship care plan, and when is the most effective time to deliver a care plan to a survivor.<sup>xxxix</sup> In a study implementing survivorship care plans for colon cancer survivors, most survivors identified the preferred time to receive a care plan as before treatment ended or within the first three months after treatment ended.<sup>xl</sup>

In addition, there is not clear evidence about how a survivorship care plan should be shared with a primary care physician and which providers should be responsible for a survivor's follow-up care. A survey of patients and providers found that patients believe their oncologists should be more involved in follow-up care than oncologists think they should be, and primary care physicians and oncologists do not agree on who should be responsible for surveillance and preventive health care for survivors.<sup>xli</sup>

Finally, another concern is the dearth of adequate research demonstrating the value of survivorship care plans and their impact on survivorship outcomes. To date, there have been only a few randomized, controlled trials evaluating the impact of survivorship care plans.<sup>xlii</sup> These studies found that the use of survivorship care plans improved communication among providers and the coordination of care, including defining which providers were responsible for specific



aspects of follow-up care. While it has been difficult to show an impact on survivorship outcomes, “it is well acknowledged that information gaps in transition of care result in suboptimal outcomes.”<sup>xlii</sup>

## Survivorship Care Plan Implementation Best Practices

Based on the survivorship care plan research conducted to date, a few best practices have emerged regarding the use of survivorship care plans. For example, a number of studies have suggested ways to reduce the time spent on the creation of survivorship care plans, such as utilizing available technology to auto-populate treatment summary information,<sup>xliv</sup> using templates with pre-specified fields, or using the revised ASCO cancer survivorship care plan template.<sup>xlv</sup> A survey of NCI community cancer center providers found that 94 percent of those who used survivorship care plan templates found them helpful.<sup>xlvi</sup> In one survey, it was suggested that a notification in the EMR flagging the need to schedule a date for the survivorship care plan to be delivered at the end of treatment would improve compliance.<sup>xlvii</sup>



A reduction in time spent on the preparation of a cancer survivorship care plan also helps to address the lack of specified reimbursement for health care providers to deliver survivorship care plans. Another suggestion is to combine an appointment to review a survivorship care plan with another follow up appointment, by scheduling it 15-60 minutes earlier depending on the time needed.

If a more simplified care plan template is used, a health care provider must either: 1) allow for sufficient time to discuss health promotion, psychosocial issues, and practical issues with a survivor, or 2) provide adequate resources on these topics.<sup>xlvii</sup>

Some other best practices described in survivorship care plan research include:

- Offering survivors a paper and electronic version of their survivorship care plans.<sup>xlix</sup>
- Providing adequate training on survivorship care for oncology and primary care providers to improve communication and define clear roles in care coordination.<sup>1</sup>
- Providing survivorship care plans to survivors either before treatment ends or within

three months after treatment ends.<sup>li</sup>

- Delegating the completion of survivorship care plans to one person on the health care team.<sup>lii</sup>
- Updating survivorship care plans when there is a diagnosed progression of disease or a new primary cancer diagnosis.
- Engaging members of the health care team other than oncologists in delivering survivorship care plans, such as oncology nurse practitioners, can alleviate staffing shortages.<sup>liii, liv</sup>
- Combining the delivery of survivorship care plans and the use of patient navigation services to improve survivors' receipt of necessary follow-up care.<sup>lv</sup>
- Engaging survivors in the development of survivorship care plans to increase the plans' cultural responsiveness and patient-centeredness.<sup>lvi</sup>
- Providing survivorship care and survivorship care plans that are age specific and appropriate, particularly for children, adolescents, young adults, and seniors.<sup>lvii, lviii</sup>
- Providing cancer survivorship care plans in languages that can be read by survivors.<sup>lix</sup>

## A Call to Action

The field of cancer survivorship and the use of cancer survivorship care plans, specifically, are still relatively new. It is clear that ongoing research is needed on the effectiveness of cancer survivorship care plans, effective and streamlined methods of delivery, and how they can improve cancer survivorship outcomes. However, existing research has indicated that survivorship care plans are well-received by cancer survivors and their primary care physicians. These are a few examples of steps that the cancer community can take to advance the use of cancer survivorship care plans and further support cancer survivors:

- Actively engaging in efforts to improve processes to deliver survivorship care plans, by testing different implementation models and sharing learned best practices.
- Encouraging third-party payors to develop a framework for reimbursement of the delivery of cancer survivorship care plans and other survivorship care.
- Encouraging developers of electronic medical record platforms to enable the auto-importation of medical record information from their platform into a survivorship care plan.



## Survivorship Care Plan Resources

- American Cancer Society: [www.cancer.org/treatment/survivorshipduringandaftertreatment/index](http://www.cancer.org/treatment/survivorshipduringandaftertreatment/index)
- American Cancer Society National Cancer Survivorship Resource Center: [www.cancer.org/treatment/survivorshipduringandaftertreatment/nationalcancersurvivorshipresourcecenter/index](http://www.cancer.org/treatment/survivorshipduringandaftertreatment/nationalcancersurvivorshipresourcecenter/index)
- American College of Surgeons Commission on Cancer: [www.facs.org/cancer](http://www.facs.org/cancer)
- Association of Community Cancer Centers: <http://acc-cancer.org/resources/cancerSurvivorship-Programs.asp>
- American Society of Clinical Oncology: [www.asco.org/practice-research/cancer-survivorship](http://www.asco.org/practice-research/cancer-survivorship)
- Cancer Survivorship E-Learning Series for Primary Care Providers: <https://cancersurvivorshipcentereducation.org>
- Cancer Survivorship in Primary Care: [www.cancersurvivorshipprimarycare.org](http://www.cancersurvivorshipprimarycare.org)
- Centers for Disease Control and Prevention: [www.cdc.gov/cancer/survivorship/index.htm](http://www.cdc.gov/cancer/survivorship/index.htm)
- Children's Oncology Group: <http://survivorshipguidelines.org>
- Cure Presents: The Nurses Guide to Cancer Survivorship Care Plans: [www.ncbi.nlm.nih.gov/nlmcatalog/?term=101655159](http://www.ncbi.nlm.nih.gov/nlmcatalog/?term=101655159)
- Journey Forward: [www.journeyforward.org](http://www.journeyforward.org)
- Institute of Medicine: [www.IOM.edu](http://www.IOM.edu)
- LIVESTRONG: [www.livestrong.org/we-can-help/healthy-living-after-treatment](http://www.livestrong.org/we-can-help/healthy-living-after-treatment)
- MD Anderson Professional Oncology Education Videos - Cancer Survivorship Series: [www.mdanderson.org/education-and-research/resources-for-professionals/professional-educational-resources/professional-oncology-education/survivorship/index.html](http://www.mdanderson.org/education-and-research/resources-for-professionals/professional-educational-resources/professional-oncology-education/survivorship/index.html)
- National Cancer Institute: [www.cancer.gov/about-cancer/coping/survivorship](http://www.cancer.gov/about-cancer/coping/survivorship)
- National Cancer Institute Office of Cancer Survivorship: <http://cancercontrol.cancer.gov/ocs>
- National Cancer Institute Adolescent and Young Adults with Cancer: [www.cancer.gov/types/aya](http://www.cancer.gov/types/aya)
- National Coalition for Cancer Survivorship: [www.canceradvocacy.org](http://www.canceradvocacy.org)
- NIH Senior Health: <http://nihseniorhealth.gov/lifeaftercancer/followupcare/01.html>
- OncoLink: [www.oncolink.org](http://www.oncolink.org)
- OncoLife Survivorship Care Plan: [www.oncolink.org/oncolife](http://www.oncolink.org/oncolife)
- Passport for Care: <http://txch.org/cancer-center/long-term-survivor-program/passport-for-care>
- Triage Cancer: <http://TriageCancer.org>

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