



Frequently Asked Questions about Survivorship Care Planning and the Comprehensive Cancer Care Improvement Act (CCCIA)

1. What is comprehensive cancer care?

Comprehensive cancer care is coordinated, integrated care that involves healthcare providers working together with patients to treat the cancer *while also addressing* side effects of treatment, psychosocial issues, and follow-up needs from the time the person is diagnosed through all the years of his or her survivorship.

People diagnosed with cancer must be treated for the disease itself *and* often for the side effects of the treatment. This can require the skills of many different types of doctors and other healthcare providers – a medical oncologist, a radiologist, a surgeon, a psychologist or psychiatrist, a nutritionist, just to name a few. And once treatment has ended, cancer survivors are often at higher risk for health complications resulting from their treatment. They are also at risk for second cancers, emotional distress, and recurrence of their original cancer. Therefore, they still need a team of providers to monitor their health throughout their lives.

2. What is The Comprehensive Cancer Care Improvement Act (CCCIA)?

The CCCIA would encourage doctors to develop and explain the plans for treatment so that patients and their families can understand the goal(s) and options available, possible immediate and long-term effects and how they will be managed, and resources for addressing other issues, if needed, such as nutrition, emotional support, and paying for care. The bill also promotes written follow-up care plans after treatment to help patients and their future healthcare providers know what should be monitored. Most cancer survivors and their primary care physicians are not aware of these issues, yet late effects of cancer treatment can include many types of health complications, like depression, bone loss, heart problems, and second cancers. Specifically, the bill allows Medicare to cover the time required for doctors to develop and communicate these plans in ways that are understood by patients.

The CCCIA is sponsored by Reps. Lois Capps (D-CA, 23rd District) and Charles Boustany (R-LA, 7th District) in the House of Representatives. It is numbered **H.R. 1844**. The CCCIA is sponsored by Sen. Mary Landrieu (D-LA) in the Senate and is numbered **S. 1773**.

3. What does the CCCIA do for cancer survivors?

Our healthcare system currently focuses on treating cancer, but it often fails to provide care that addresses symptoms and side effects of treatment, as well as emotional, social, spiritual, and practical needs of the cancer survivor. Nor does it frequently address or plan for the possible late-term effects of cancer and its treatment. A comprehensive cancer care model that combines primary treatment with management of the side effects of treatment, as well as the psychosocial and practical effects of having cancer, will greatly improve cancer care in the United States.

Specifically, the CCCIA encourages oncologists to develop *written* comprehensive treatment plans, treatment summaries, and follow-up care plans in consultation with their patients. It does this by providing Medicare reimbursement for the time it takes doctors to create these plans and talk them over with the patient. (Developing a written treatment plan, treatment summary, and follow-up care plan requires a considerable amount of time and effort. In many cases, an entirely separate doctor/patient consultation is needed to address the issues, complete the documents, and ensure that both the doctor and the patient have a clear understanding of next steps.)

This approach would give patients an easy-to-use document that they could take with them to every provider who might need to see a record of what treatment was administered in the past and what needs to be monitored in the future.

4. Why is cancer care planning important?

Cancer is actually many different diseases, and most of them are complicated. For nearly all types of cancer there are multiple possible treatment options. Each possible option may have a different set of risks, side effects, and potential level of effectiveness. A structured process for planning treatments ensures that the patient has a clear understanding of the treatment goals, the pros and cons of various treatment options, a plan for managing side effects and symptoms, an assessment of psychological needs, and, if appropriate, an option to participate in a clinical trial. By writing out the plan, the patient can review the discussion later, share it with caregivers and other providers, and refer to it as needed.

Likewise, having a written summary of the treatments received and their outcomes is important for quality follow-up care. Because this information is usually spread throughout a thick medical record, having a “cheat sheet” is an important way to highlight the key information future healthcare providers need to know.

Follow-up plans are important because cancer and its treatment can have a wide variety of effects that can show up long after treatment has ended. People who have had one cancer are at higher risk for recurrence of that cancer. The treatments for cancer, particularly radiation therapy, can also raise the risk of second cancers. Treatments may also raise the risk for heart problems, hypertension, fertility issues, bone loss, and depression. A follow-up plan acknowledges the likely medical and psychosocial issues that may come up in the future and suggests screenings and resources to address these issues.

5. Do all cancer patients need follow-up care?

Yes, all cancer patients need at least some follow-up care. All cancer patients who have completed treatment need to be monitored for at least some period of time to watch for recurrence of their cancer. Some cancer survivors experience extended or even permanent side effects during treatment that may require management after their anti-cancer treatment ends. And some cancer survivors have had types of treatment that place them at risk of having late-occurring side effects, which develop years after their treatment has ended.

A lot of information about which kinds of follow-up care cancer survivors may need is already known, but some is still being learned. All patients need to be given the most up-to-date information about their treatments, conditions, and risks at the time treatment ends so they can get the follow-up care that is best suited to their cases.

6. What goes into comprehensive care planning?

As defined in the CCCIA, *comprehensive cancer care planning* is the creation and communication of written documents that detail the care to be provided to the cancer patient, including the diagnosis, treatment and goals, and follow-up care recommendations.

It should include a **treatment plan** that indicates the diagnosis and outlines the goals and intended course of treatment, as well as possible side-effects and plans to manage them. It should also include a psychosocial assessment, a discussion of advance directives, and a discussion of participating in a clinical trial, if appropriate. This should be furnished to the patient in an easy-to-read, culturally appropriate, written document at the start of treatment and updated if a significant change in treatment is made.

Comprehensive cancer care planning should also include a written *follow-up care plan* (also called a *survivorship care plan*) that includes the diagnosis, a summary of the treatments delivered (including surgeries, the names of drugs and dosages and the dosages and frequency radiation) and the patient’s response to them. Wherever possible, the potential long-term effects of treatments should be noted. The follow-up care plan should also include a written document that provides information about necessary post-treatment care, preventative practices and resources for further information and support. It should include specific information about the timing and content of recommended follow-up (for example, screening tests for recurrences and/or secondary cancers, follow-up visits with the oncologist, etc.); recommendations about preventative practices and how to maintain health and well-being (for example, nutrition, exercise, and emotional support); information on employment rights as a cancer survivor and access to health insurance; and availability of support services in the local community.

These cancer care plans should all be delivered to the patient in easy-to-read written documents and the doctor and patient (and family members or caregivers) should discuss the contents.



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7. Why is it so important that these plans be written? Isn't it in the medical record?

Past treatment information is in the medical record, but after months or years of treatment, that record can grow pretty thick! Moreover, doctors retire or move to new hospitals, children who had cancer grow up and leave home, people move to new towns – and medical records can be hard to find years later. Having these written documents is also an important tool that cancer survivors can carry with them and share with new healthcare providers, such as their primary care physician, other specialists, a new oncologist, or doctors in the emergency department.

Moreover, taking the time to develop a written survivorship care plan encourages the doctor and patient to discuss the treatment and side effects and plan for what may come about in the future. It is a time when the patient can ask questions and make informed decisions about how to move forward.

8. How many Americans will be affected by this bill if it passes?

Nearly 12 million Americans are cancer survivors and almost 1.5 million Americans receive a cancer diagnosis every year. Roughly 65 percent of Americans with cancer are eligible for Medicare.

Moreover, because private insurance companies often follow Medicare's lead, it is expected that once Medicare begins paying for written survivorship care plans, other insurers will consider doing the same, eventually making written survivorship care plans the standard of care for all cancer survivors.

9. I'm not on Medicare and won't be for a while, so why is the legislation important to me?

Other insurance companies often follow Medicare's lead on what to cover, so it is expected that once Medicare recognizes the value of survivorship care plans, other insurers will consider doing the same. The goal is for written survivorship care plans to become the standard care for all cancer survivors.

10. Who else supports this legislation?

The CCCIA is supported by more than 30 leading cancer advocacy groups – including the American Cancer Society and the Lance Armstrong Foundation – and National Cancer Institute-designated cancer care centers across the country. It also has support from the American Society of Clinical Oncology, the world's leading professional organization representing physicians of all oncology subspecialties who care for people with cancer.

For more information, visit NCCS's Take Action center at <http://www.canceradvocacy.org/get-involved/> or contact us at advocacy@canceradvocacy.org or 301.562.2772.