

Cancer Survivorship Care Planning

There are currently 10 million Americans who are considered cancer survivors, and their ranks are growing rapidly as more than a million new cases of cancer are diagnosed each year. Unfortunately, the current U.S. health care system is failing to deliver the comprehensive and coordinated follow-up care cancer survivors deserve. Too many survivors are lost in transition once they finish treatment. They move from an orderly system of care to a “non-system” in which there are few guidelines to assist them through the next stage of their life or help them overcome the medical and psychosocial problems that may arise.

Every cancer survivor should have a comprehensive care summary and follow-up plan once they complete their primary cancer care that reflects their treatment and addresses a myriad of post-treatment needs to improve their health and quality of life.

Elements of a Survivorship Care Plan

Record of Care

Upon discharge from cancer treatment, including treatment of recurrences, every patient should be given a record of all care received and important disease characteristics. This should include, at a minimum:

- Diagnostic tests performed and results.
- Tumor characteristics (e.g., site(s), stage and grade, hormonal status, marker information).
- Dates of treatment initiation and completion.
- Surgery, chemotherapy, radiotherapy, transplant, hormonal therapy, gene or other therapies provided, including agents used, treatment regimen, total dosage, identifying number and title of clinical trials (if any), indicators of treatment response, and toxicities experienced during treatment.
- Psychosocial, nutritional, and other supportive services provided.
- Full contact information on treating institutions and key individual providers.
- Identification of a key point of contact and coordinator of continuing care.

Standards of Care

Upon discharge from cancer treatment, every patient and their primary health care provider should receive a written follow-up care plan incorporating available evidence-based standards of care. This should include, at a minimum:

- The likely course of recovery from treatment toxicities, as well as need for ongoing health maintenance/adjuvant therapy
- A description of recommended cancer screening and other periodic testing and examinations, and the schedule on which they should be performed (and who should provide them).
- Information on possible late and long-term effects of treatment and symptoms of such effects.
- Information on possible signs of recurrence and second tumors.
- Information on the possible effects of cancer on marital/partner relationship, sexual functioning, work, and parenting, and the potential future need for psychosocial support.
- Information on the potential insurance, employment, and financial consequences of cancer and, as necessary, referral to counseling, legal aid, and financial assistance.
- Specific recommendations for healthy behaviors (e.g., diet, exercise, healthy weight, sunscreen use, virus protection, smoking cessation, osteoporosis prevention). When appropriate, recommendations that first degree relatives be informed about their increased risk and the need for cancer screening (e.g., breast cancer, colorectal cancer, prostate cancer).
- As appropriate, information on genetic counseling and testing to identify high risk individuals who could benefit from more comprehensive cancer surveillance, chemoprevention, or risk reducing surgery.
- As appropriate, information on known effective chemoprevention strategies for secondary prevention (e.g. Tamoxifen in women at high risk for breast cancer; aspirin for colorectal cancer prevention).
- Referrals to specific follow-up care providers, support groups, and/or the patient’s primary care provider.
- A listing of cancer-related resources and information (Internet-based sources and telephone listings for major cancer support organizations).

Questions Survivors Should Ask

Like most patients, cancer survivors want to be empowered to take care of themselves and remain healthy. Once cancer treatment ends, there are some questions every patient should be asking their doctor to be informed about their care and to know what they can expect next. These include, but are not limited to the following:

What treatments and drugs have I been given?

Patients should require their doctor to provide a written record detailing the type of cancer they had, the treatments and drugs they received, and the potential side effects of these treatments.

Do I need to seek follow-up care?

Patients should be given a written cancer survivorship plan that would detail what kinds of screening or tests they should be receiving post-treatment and a schedule of when they should be following up with their primary care or oncology provider to have these performed.

Will I get cancer again?

Oncology providers should explain, both verbally and in writing, the risks of secondary cancers or recurrent cancers and what signs or symptoms to look for.

What should I do to maintain my health and well-being?

Patients should be advised on the benefits of healthy diets and routine exercise and the perils of not routinely using sunscreen or continuing to smoke. Patients also should ask their doctors, if appropriate, about whether they should inform close relatives about their increased risk of cancer and need for cancer screening.

Even though I survived cancer, will I feel differently physically?

Cancer treatment has a different effect on everyone, and for some survivors, there are serious side effects from treatment. Providers need to educate patients and make them aware of the possible short and long term effect that may arise. Radiation could affect a person's heart, stamina, or fertility. Patients may feel overly anxious or depressed about the possibility of getting cancer again. You should ask your doctor how treatment could affect your long-term health and mental functioning.

Will I have trouble getting health insurance or keeping a job because of my cancer?

Having cancer can affect access to health or life insurance, the ability to keep a job, as well as job mobility. Providers should be prepared to offer cancer patients information about what resources are available if they face employment discrimination or are unable to access or keep health and life insurance.

Are there support groups I can turn to?

Your provider should be able to provide a useful list of community or nationally based cancer-related organizations or other groups that can offer support with or information on survivorship issues and challenges.

Now that I've finished treatment, who on the cancer team will be responsible for monitoring my care?

Patients should know who will be the main point of contact working with their primary care provider to coordinate follow-up care related to their cancer treatment.