

# Focus ON...

# Cancer and survivorship



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# Cancer survivorship

## Understanding cancer survivorship care

By Patricia Leighton, MSN Ed, OCN

**C**ancer survivorship refers to the entire process of living with, through, and beyond cancer. A person is considered a cancer survivor from the time of diagnosis until death. (An acute cancer survivor is a person who is disease-free after completing cancer treatment.) Unfortunately, many patients enter survivorship with insufficient direction as to what to do. For instance, a survey of 1,130 oncologists published in the *Journal of Clinical Oncology* found that although about two-thirds said they always or almost always discuss survivorship, only a third discussed whom patients should see for follow-up care, and fewer than 5% provided patients with a written plan for their survivorship care. The survey also found that of 1,020 primary care providers, only 12% regularly discussed survivorship care recommendations.

Nurses' strength in educating patients can be lever-

aged to improve survivorship care. For example, oncology nurse navigators play an integral role on multidisciplinary, hospital-based teams of oncology professionals. Together, team members care for the needs of the whole patient, providing interventions that address not just the disease but the patient's mind and body. This article enhances nurses' awareness of the challenges cancer survivors face, including fear of cancer recurrence and late physiologic effects (such as fatigue and cognitive effects) of treatment. It also explains the role of the survivorship nurse navigator in an academic, hospital-based survivorship program. (See *Survivorship nurse navigator: Overview and daily responsibilities*.)

### Survivorship challenges

In 2014, an estimated 1.6 million new cancer cases will be diagnosed in the United States and more than a half-million people will die of cancer. About 14 million Americans are cancer survivors.

Extended survivorship from cancer used to be a rare occurrence. But with new medical advances, early detection, and more targeted treatments, the odds of surviving have markedly improved in many cancers. A

prime example of a cancer with a changed natural history due to targeted therapies is multiple myeloma. Many targeted therapies are long term, and adherence plays a pivotal role in achieving long-term overall survival. The importance of keeping follow-up appointments and taking treatments correctly for the prescribed duration can't be stressed enough. Educating patients to keep appointments, as well as monitoring adherence for such agents as immunomodulatory drugs and proteasome inhibitors is crucial throughout acute treatment and long-term surveillance.

As more cancer patients survive their diagnosis, the lingering effects of cancer therapy can give rise to new challenges, such as post-treatment effects (for instance, fatigue and cognitive changes). Other issues include the psychological (for

example, fear of recurrence) and financial (for example, continued insurance coverage) effects of living with cancer in terms of a "chronic" disease. Formal survivorship care can help patients manage these problems.

The American College of Surgeons (ACoS) recommends that programs accredited by the Commission on Cancer (CoC) implement a process to provide sur-



aged to improve survivorship care. For example, oncology nurse navigators play an integral role on multidisciplinary, hospital-based teams of oncology professionals. Together, team members care for the needs of the whole patient, providing interventions that address not just the disease but the patient's mind and body.

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## Survivorship nurse navigator: Overview and daily responsibilities

At Greenville Health System Cancer Institute in Greenville, South Carolina, the survivorship nurse navigator communicates, collaborates, and coordinates with other members of the multidisciplinary survivorship team to ensure efficient, effective patient care. The nurse navigator orchestrates and coordinates direct and indirect care and promotes communication both among the survivorship team and with the cancer survivor.

Daily responsibilities include initial intake and communication of all survivorship referrals. The navigator notifies the survivor on receipt of the oncologist's referral for survivorship care, educates the patient about the purpose of the survivorship care-planning visit, tells the patient which clinicians will participate in the visit, and previews the information, resources, and education the patient will receive.

Before each survivorship visit, the navigator extracts and prints data from the patient's electronic medical record and prepares the survivorship care-plan document. He or she carefully scrutinizes the record to identify previously documented survivorship challenges. The navigator provides a summary of these challenges on a team communication report and disseminates the report to the multidisciplinary team before the patient's visit.

Shortly before the patient's first clinic visit, the survivorship multidisciplinary team "huddles" to discuss how team members can meet the patient's needs and challenges effectively. Then the nurse navigator greets and assesses the patient; obtains vital signs, a fatigue score, and body mass index; and reconciles the patient's medication list. During the multidisciplinary visit, the navigator documents additional needs identified by the team and provides the resources or referrals required to meet the patient's needs.

Survivorship care to all patients who've completed cancer therapy by 2015; this care should include appropriate follow-up and surveillance. The 2005 Institute of Medicine report "From Cancer Patient to Cancer Survivor: Lost in Transition" recommends a survivorship care plan and appropriate follow-up methods for all cancer patients, to bridge the gap from active treatment to survivorship. Bridging that gap includes addressing the challenges of both the disease and its treatment.

### Some problems cancer survivors may face

The uncertainty of a cure and fear of cancer recurrence or progression are common among survivors and can cause pronounced anxiety. Many patients live from day to day not knowing what their "new normal" is. This makes it hard for them to interpret the physical ailments they may be experiencing. Some may fear a simple headache or joint pain means their cancer has returned or progressed. The anniversary of the cancer diagnosis may be especially distressing, causing the patient to avoid scheduled follow-up exams. Approximately 29% of cancer survivors experience depression, anxiety, and vulnerability for fear of recurrence. Nearly 20% may meet the criteria for posttraumatic stress disorder. Fear of recurrence can have a significant domino effect: patients may become so anxious that they isolate themselves socially, which can lead to work-related, financial, and other difficulties.

### Cognitive effects

Long-term cognitive effects of cancer therapy can last months or even years after treatment ends. Such impairment, sometimes called chemo brain, can be life-altering. Radiation and hormonal therapy also may cause cognitive and memory changes. Approximately 20% to 30% of cancer patients report some degree of thought impairment, described by many as difficulty forming words, memory loss, and poor concentration. The degree of cognitive impairment varies. Some survivors report sporadic impairments; others say the effects are long-lasting, decrease their quality of life, or cause permanent disability.

### Fatigue

Fatigue can be a debilitating effect of both cancer and its treatment. The National Comprehensive Cancer Network (NCCN) describes cancer-related fatigue as "a distressing, persistent, subjective sense of physical, emotional, and/or cognitive tiredness or exhaustion related to cancer

or cancer treatment that is not proportional to recent activity and interferes with usual functioning." Fatigue can disrupt the patient's normal routine and affect quality of life. Activities of daily living may become a challenge. Extreme exhaustion may cause patients to avoid activities they previously performed independently.

### Survivorship care model

As patients approach completion of their cancer treatment, they may wonder, "What steps should I take to return to my normal life?" Transitioning from acute survivorship (active treatment) to extended survivorship (after completion of treatment) can provoke various reactions, depending on a survivor's specific experience. Survivorship care helps smooth the transition from a primary oncologist's care to a survivorship care model. Ideally, a survivorship care plan should be established at diagnosis and updated as a patient progresses through the cancer journey.

### Survivorship visit

At Greenville Health System Cancer Institute, the treating oncologist refers patients to a survivorship care team after the initial cancer treatment ends. The team uses a patient-centered, multidisciplinary approach. Survivor visits are conducted in a private nonclinical environment. Before meeting the entire survivorship team, patients fill out a 12-item questionnaire, called a distress inventory.

Then the patient and team members—a medical oncologist, nurse navigator, oncology registered dietitian, and oncology licensed social worker—have a roundtable discussion. Members of each discipline intervene based on collective and collaborative assessment of the patient's needs. The patient's nutritional status and needs (for instance, weight gain or loss and daily eating habits) are discussed and the dietitian provides nutritional counseling. In some cases, an exercise routine is recommended to help the patient lose or gain weight as needed, improve energy levels, and increase stamina and self-esteem. The survivorship physician may order oncology rehabilitation and teach the patient about the benefits of combining dietary interventions with exercise. At the patient's request, evidence-based complimentary integrative therapies (such as acupuncture) are included.

The distress management tool the patient completed earlier is reviewed by the survivorship physician, social worker, and nurse navigator. They screen for categorical items identifying distress, such as practical issues (insurance or housing), physical issues (fatigue and appearance), family issues (child or partner relationships), emotional issues (fear and worry), and spiritual (faith) issues. The social worker and physician address the items that indicate a significant level of distress. (While some distress is expected, about one-third of cancer patients experience a significant amount. Distress doesn't necessarily result from the cancer diagnosis or experience, but it plays a significant role in the patient's coping and compliance.)

The team discusses the survivorship plan with the patient and gives the patient a copy, along with the pathology report. The plan details the patient's entire cancer experience. A three- to four-page document, it's prepared before the patient's visit by extracting data from the medical record—including demographic information, healthcare team members' names, diagnosis date, cancer type and stage, chemotherapeutic agents received and their cumulative dosages, family cancer history with possible genetic risks, comorbidities, treatment toxicities and adverse effects, recommended surveillance schedule, and referrals based on the patient's needs. For instance, some patients may need densitometry testing, nutritional education and counseling, oncology rehabilitation, and psychosocial support and counseling. The plan include guidelines for recommended follow-up care throughout survivorship.

### Significance of survivorship education

Surviving cancer provides a unique incentive for the patient to make positive lifestyle changes and adopt a healthier lifestyle. Behavioral changes, such as adhering to a new diet, starting an exercise routine, or practicing mindfulness to control anxiety, can prove difficult. However, the cancer diagnosis and the feeling of

vulnerability it brings can provide a teachable moment that catalyzes the patient to make behavior changes. The survivorship visit is an opportune time for the team to provide patient education about long-term treatment effects and the benefits of good nutrition and exercise.

One goal of the survivorship visit is to encourage patients to share the care plan with their primary healthcare team to help them understand the patient's needs and participate in care. The care plan empowers patients to take control through knowledge and specific resources that help them grow comfortable with their "new normal".

### On the path to prolonged survival

Cancer survivors desire a return to normal. To achieve their new normal, they need healthcare education and surveillance measures specific to their health and wellness needs. With cancer survival rates increasing, the need for management of long-term side effects, education, surveillance for disease progression and secondary cancers, and promotion of physical, psychological, and psychosocial well-being become priorities. Survivorship care provides the education and support needed for patients to adopt and adapt to positive lifestyle changes. Nurse navigators have the opportunity to teach and give direction to cancer survivors, guiding them on the path of prolonged survival. ★

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### Selected references

- American College of Surgeons. Cancer Program Standards 2012: Ensuring Patient-Centered Care. <http://facs.org/cancer/coc/program-standards2012.pdf>. Accessed March 7, 2014.
- Blanch-Hartigan D, Forsythe LP, Alfano CM, et al. Provision and discussion of survivorship care plans among cancer survivors: Results of a nationally representative survey of oncologists and primary care physicians. *J Clin Oncol*. April 21, 2014.
- Centers for Disease Control and Prevention. How many people are cancer survivors; 2012. [http://www.cdc.gov/cancer/survivorship/basic\\_info/index.htm](http://www.cdc.gov/cancer/survivorship/basic_info/index.htm). Accessed March 12, 2014.
- Miguel J F, Schlag R, Khuageva N, et al. Persistent overall survival benefit and no increased risk of second malignancies with bortezomib-melphalan-prednisone versus melphalan-prednisone in patients with previously untreated multiple myeloma. *J Clin Oncol*. 2013;31(4):448-55.
- Miller KD. *Medical and Psychosocial Care of the Cancer Survivor*. Sudbury, Mass: Jones and Bartlett; 2009.
- National Cancer Institute. SEER Stat Fact Sheets: All Cancer Sites; 2012. <http://seer.cancer.gov/statfacts/html/all.html>. Accessed March 7, 2014.
- Survivorship. American Society of Clinical Oncology; 2012. [www.cancer.net/survivorship](http://www.cancer.net/survivorship). Accessed March 7, 2014.
- Taking charge of follow-up care. National Comprehensive Cancer Network. [www.nccn.org/patients/resources/life\\_after\\_cancer/survivorship.aspx](http://www.nccn.org/patients/resources/life_after_cancer/survivorship.aspx). Accessed March 10, 2014.



# Teach-back essentials for cancer survivors

Use this method to help patients grasp the information they need.

By Melanie Haney, MSN, RN, PCCN, and Jessica Shepherd, BSN, RN

**P**atients who are cancer survivors may require education on a wide variety of topics, from nutrition to long-term follow-up needs. It's vital that nurses ensure patients understand the information they are given. One useful technique is teach-back.

## What is teach-back?

Here's how teach-back works: Ask the patient to explain the information you've just presented, so you can confirm if he or she comprehends it.

For instance, you know that it's important for patients to complete their full course of therapy. One reason they may not complete therapy is difficulty with side effects. You may have to work with patients to ensure they can manage these effects.

If you've just taught a patient strategies she can use to manage fatigue, ask an open-ended question or make a statement that implicitly asks for a response; for instance: "Tell me which ideas you plan to try." Based on the patient's response, you can determine whether she understands the information or needs further teaching.

Break up information into smaller chunks to make it easier for patients to learn the material. One continuous hour of teaching is a large block of time for someone to absorb and retain information. Also be aware that "chemo brain," which refers to such cognitive changes as poor memory after cancer treatment, can affect ability to learn.

For the most effective education, hold teach-back sessions as soon as the patient's learning needs are identified. For instance, if a patient needs to complete one year of therapy on a treatment, it's important to discuss the treatment plan and goals up front to ensure the patient understands. To maximize effectiveness, also follow the guidelines below.

## Encourage family presence

Be aware that family presence is crucial for interactive learning and asking good questions. The more people who ask questions and remember what they've learned, the better off the patient is. Giving family members the information they need to help a loved one is essential to effective care. Of course, it's the pa-

tient's choice as to which family members or friends to include.

## Make it hands-on

Hands-on teaching is a key aspect of the teach-back method. Say, for instance, you're focusing on using a pillbox to prepare a week's supply of your patient's medications. Have the patient fill the box, rather than simply tell him about it. Another example: when explaining the treatment schedule for a patient who is taking or receiving cancer therapy, you could provide a calendar of scheduled treatments the patient can mark off as they are completed.

## Assess baseline knowledge

You can use the teach-back method to evaluate the patient's baseline knowledge of a topic and determine what other providers have already taught. Patients may tune out if they already have a good understanding of the topic at hand. Start by asking what the patient already knows to help determine if you need to review the basics. If the patient already understands the basics, move on to more complex information.

## Schedule sessions in advance

Schedule teach-back sessions at a time that's convenient for the patient, rather than on the spur of the moment. This helps ensure the patient will be alert and mentally prepared when you arrive. Also, it means a family member is more likely to be present. Finally, tell patients at the beginning of the session that you'll be asking questions. If they know they'll be quizzed, they may be more attentive.

## Improving quality of life

Using teach-back helps ensure cancer survivors understand what they are learning so they can apply the information to improve their quality of life.

To learn more about the teach-back method, download this file at the NC Program on Health Literacy website: [www.nchealthliteracy.org/toolkit/tool5.pdf](http://www.nchealthliteracy.org/toolkit/tool5.pdf). ★

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