First Steps for the Newly Diagnosed: The Cancer Survival Toolbox

[TRACK 1: INTRODUCTION]

[TRACK 2: SURVIVOR STORIES: GATHERING INFORMATION]

[TRACK 3: SURVIVOR STORIES: YOUR CANCER CARE TEAM]

[TRACK 4: SURVIVOR STORIES: YOUR CANCER CARE PLAN/SECOND OPINIONS]

[TRACK 5: SURVIVOR STORIES: OTHER RESOURCES AND HOW TO FIND THEM]

[TRACK 6: SURVIVOR STORIES: REVIEWING YOUR HEALTHCARE POLICY]

[TRACK 7: SURVIVOR STORIES: ASKING FOR HELP]

[TRACK 8: SURVIVOR STORIES: WHO TO TELL]

[TRACK 9: SURVIVOR STORIES: TELLING YOUR EMPLOYER]

[TRACK 10: SURVIVORSHIP CARE PLANNING]
Although it may seem too early for you to be thinking about your life after treatment and long-term survivorship, now may be a good time to start putting together your “survivorship care plan.” This plan should contain the results of diagnostic tests and information about the cancer and the treatment that was used. Eventually, it should list immediate and lasting side effects that you had, and a list of plans for follow-up care. Contact information for questions about the course of treatment should be listed, along with the name and contact information of the doctor who managed your care. You should be familiar with the known long-term and late effects of treatment, signs and symptoms to watch for, and who to contact if they occur. Depending on your specific needs, your survivorship care plan may also include referrals to a fertility specialist, sex therapist, genetic counselor, or a psychiatrist or psychologist who specializes in working with cancer survivors. Financial counselors, insurance information, and estate planning specialists may also be helpful in your particular situation. Eventually, your care plan should also contain resources to help you adopt changes for a healthy lifestyle, such as community resources for fitness, exercise, and stress reduction programs, nutritional counseling, and smoking cessation programs designed for cancer survivors. Check with your cancer care team, physical therapist, local American Cancer Society office, or support group, a YMCA, fitness center, or yoga or Pilates studios for information about programs you might use. Internet-based searches might also locate programs in your area.

It’s important to develop a survivorship care plan. If your cancer care team doesn’t offer you the chance to create such a plan, you can take the lead to make it happen.

The first step in creating a survivorship care plan is learning more about what’s included, and then asking your oncologist to work with you to create one. Survivorship care plans make sure survivors and doctors—oncologists, primary care physicians, or other doctors you may see—are on the same page about treatment and post-treatment follow-up care. An award-winning program called Journey Forward is a web-based tool that allows survivors and their cancer care teams to develop a customized plan. It will help you and your cancer care team create a summary of your treatment, and, once you’re done with treatment, build a roadmap—or follow-up care plan—for your care moving forward. You can print out this plan and keep a copy for your records, and also give it to other healthcare professionals you may see in the future. Learn more about this free program at JourneyForward.org, or in the online Resource Booklet.

In addition, the American Journal of Nursing published the article “The Cancer Survivor’s Prescription for Living” in April 2007. This article contains a care planning model called “A Prescription for Living,” which can be used as is, or revised to more closely fit your needs. The model can be accessed on the American Journal of Nursing’s Web site – www.nursingcenter.com/ajncancersurvivors. NCCS also has more information on care planning at www.canceradvocacy.org/careplanning.

Thank you for taking the time to listen to this program. We hope the information provided helps you cope in the coming days and weeks, and helps you to arrive at a “new normal” lifestyle.

As a final note, please refer to the online Resource Booklet for a list of nationwide resources specifically for cancer survivors. Two organizations you may want to contact are:

- The National Coalition for Cancer Survivorship, which has free booklets on remaining hopeful after a cancer diagnosis, advocating for yourself and others, working with your healthcare team to make sure your needs are met, navigating insurance issues, and understanding your employment rights. NCCS can also provide you with information on
cancer survivorship issues. Their number is 1-888-650-9127, or visit www.canceradvocacy.org.

- The Counseling Line from Cancer Care at 1-800-813-HOPE for one-on-one counseling, telephone support groups, and referral to other resources. Their number again is 1-800-813-H-O-P-E or 1-800-813-4673.

[Narrator]

This is the end of the Cancer Survival Toolbox program entitled “First Steps for the Newly Diagnosed.” You may also want to listen to other Cancer Survival Toolbox programs such as “Communicating,” “Making Decisions,” and “Standing Up for Your Rights.”