

### [TRACK 3: SURVIVOR STORIES: INSURANCE AFTER TREATMENT]

#### Robert, early 20s: Part I

[Robert]

It seems crazy for me not to have health insurance. You would think I would know better, right? I mean, after all, I just finished college, I have a business degree, and I just got a job. But, I just can't afford health insurance right now. You see, I had just started my last year of college when I was diagnosed with Hodgkin disease I had student health insurance then, and it paid for all of my medical tests and all of my treatment. Now that I'm out of school, I am not eligible for the student health insurance or my family's insurance. The company I work for is too small to offer insurance to me or the other 15 employees. My cancer history popped up as a "pre-existing condition" when I tried to get private insurance and I was turned down. I found another company that would offer me coverage, but just paying for the insurance would cost almost my entire salary. I did well after I finished treatment and I wanted to put my cancer behind me. But my doctor made it clear that I should have regular medical check-ups for the rest of my life. At first, my doctor wanted me to come in for a check-up every 3 months. Then, she asked me to come back every 6 months. Eventually, I would only need to have a check-up once a year. At each check-up, I had tests that showed that there was no more cancer, and each time the doctors seemed happy that I was doing so well. But, I was always worried about how I would pay for these check-ups. I thought about canceling my next appointment. I asked the nurse if she was sure I really needed to keep coming to these appointments. After all, I am O.K., right? But, the truth is, I was embarrassed about not having insurance. I felt like people would think I was just irresponsible or careless. But, the nurse helped me talk to the doctor about this - and then went with me to talk to the social worker and finance counselor at the clinic. I was relieved to find out that the cancer doctor is willing to see me for my follow-up appointments even though I don't have insurance. The counselor encouraged me to keep looking for insurance that I could afford, and the social worker offered to help me look. The social worker warned me to expect that I would probably not be able to be insured for cancer, but that I should still try to get insurance for accidents and other illnesses. And, I do hope to have a family someday, and I know that getting a family insurance plan will be important. Plus, there is always the chance I will move to another state and need to find new doctors - and then I'll need to explore ways to keep getting my follow-up care.

[Narrator]

Linda reminds us that finding ways to pay for care is a long-term process for cancer survivors.

[Social Worker]

Many cancer survivors face the problem of finding and getting good, consistent follow-up care. With many cancers, there is a chance that the disease will come back, or "recur." Other medical problems, or even another form of cancer, could develop. It is important that cancer survivors make sure to tell all health-care team members about their cancer history and the kind of treatment that they have received. This way, if the cancer does come back, it will be found early. With early detection, the right kind of treatment can be started quickly, and hopefully cut down on the chance of more problems. Other treatment-related health problems could be discovered early too and treated right away so that they don't become more serious.

#### Robert, in his 20s: Part II

[Robert]

At first, I wondered if I would ever be able to get insurance after having cancer. My social worker warned me that it might be difficult, but I was encouraged just to know that it was not impossible. I

started by exploring the laws in my state that determine what kind of health plans are offered. I called the state insurance department for information and spelled out my specific insurance needs. These laws can be different in each state. I found that my state has a government-sponsored insurance program that has a high-risk pool for people in my situation. It offers me the chance to get into an insurance program even though I don't qualify for other kinds of insurance. I found out that I would be eligible for what they call an "open enrollment period" - that's when everyone, no matter what kind of medical history they have, can sign up for an insurance plan.

[Social Worker]

Cancer survivors have to deal with a lot of change and upheaval in their lives, so the idea of changing to a job that provides health insurance may be too much to think about for a while. But, after things settle down, that is something that might make sense to think about. Certain types of jobs or companies are more likely to offer insurance as an employment benefit. Usually, the larger the company and the more employees, the easier it is to get insurance. Jobs in companies where employees belong to labor unions usually offer insurance as part of the job benefits package. Group insurance plans offered by companies often include an "open enrollment" period - a designated time during the year when employees select or change their health plans. When people enroll during this open enrollment time, they are usually not asked for information about their health history that has prevented them from getting insurance in the past. Government jobs offer a certain amount of protection since Federal and some state laws help protect cancer survivors against employment discrimination. Government employees have some very good advantages: their insurance goes with them when they change government jobs, and they do have the right to sue their managed care insurance provider - a right that is not always there for people with other kinds of insurance or managed care plans. Government jobs also extend benefits like insurance to a spouse who might be unable to get his or her own insurance.

[Robert]

I am young, and I hope that I have a long and healthy life ahead of me. I realize that I will probably see many doctors for different things throughout my life. I used to wonder IF I should tell my new doctors about my cancer even when I was seeing them for a non-cancer reason. Then, in a group meeting I went to, a nurse who is also a cancer survivor said that it will always be important for any doctor or nurse who provides me care to know about my cancer and the specific treatment I received. This way, they can order the right tests and make sure that I am not having any problems related to my past therapy. Then I thought, wow - my therapy was so complicated - I had surgery, then chemotherapy, and then radiation. How would I ever remember all I was supposed to tell the new doctors? We talked about this in my group.

[Narrator]

Robert learned about Cancer Care Planning at his support group meeting. Many cancer center and oncology office staff help their patients create a personalized follow-up care plan that includes a summary of their cancer treatments, possible long-term effects of the treatments, and needed follow-up. Some of these plans also suggest changes that people with cancer can make in their daily lives that can help to make them healthier – resources to help people stop smoking, improve nutrition and exercise, and cope with stress better. There are several free programs, like Journey Forward at [www.journeyforward.org](http://www.journeyforward.org), that can help you work with your doctor to create an electronic treatment summary and follow-up care plan.

The group leader also suggested ways to collect medical records. Start with talking to your cancer doctors and ask for copies of your medical records. Then, make a notebook - maybe use a 3-ring binder that can be added to as time goes on. Test reports can go into pockets in the binder. Because of Robert's insurance problems the group leader suggested that the notebook

should have a section especially for all the letters back and forth with his insurance company or Medicaid or Medicare. It would include information about what was paid for, what was not, letters, responses, contacts, and all the resources that have been used. Since other people in the group had insurance problems like Roberts, they liked this idea a lot.

It is a good idea to take the Follow-Up Care Plan and Treatment Summary or notebooks with your records to any new doctor or clinic you go to, whether it is an office, a free clinic, a county or government facility, a community hospital, or a university medical center. This information will also help social service agencies find the best resources for your particular needs. It is best not to let anyone else keep the Follow-Up Care Plan or binder. You can let doctors or clinics make copies of the information in the Follow-Up Care Plan or binder, but to be sure to get it - and all that it contains - back.

[Robert]

I can understand - it would be very difficult, or impossible, to replace the information I had gathered. Sometimes I felt frustrated by how hard it was for me to find and get good cancer care. I had to rely on a couple of friends, my family, and the doctors, nurses and social workers a lot of the time - especially to help guide me to the right places. But, it was worth it. I know I can keep getting the follow-up care I need for my cancer - that any problems I might develop will be picked up early, and the right kind of treatment will be started. Of course, I hope that won't be necessary! I was able to get insurance during an open enrollment period. And, if someday I get another job or move, I know what to do to take care of myself and stay healthy. I am a survivor - and all the work has been worth it.