After Kaposi Sarcoma Treatment

Living as a Cancer Survivor

For many people, cancer treatment often raises questions about next steps as a survivor.

- Living as a Kaposi Sarcoma Survivor

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For some people with Kaposi sarcoma (KS), treatment may remove or destroy the cancer. The end of treatment can be both stressful and exciting. You may be relieved to finish treatment, but it is hard not to worry about cancer coming back\(^1\). This is a very real concern for those who have KS, since treatments often do not cure the disease.

For many people with KS, the cancer never goes away completely. Some people may get regular treatments with chemotherapy, radiation therapy, or other therapies to try to help keep the cancer in check. Learning to live with cancer that does not go away can be difficult and very stressful. See Managing Cancer As a Chronic Illness\(^2\) for more about this.

Life after Kaposi sarcoma means returning to some familiar things and making some new choices.

Follow-up care
During and after treatment, it’s very important to go to all your follow-up appointments. During these visits, your doctors will ask about symptoms, examine you, and order blood tests or imaging studies such as CT scans or x-rays. Follow-up is needed to see if the cancer has come back, if more treatment is needed, and to check for any side effects. This is the time for you to talk to your cancer care team about any changes or problems you notice and any questions or concerns you have.

Almost any cancer treatment can have side effects. Some last for a few weeks to several months, but others can be permanent. Don’t hesitate to tell your cancer care team about any symptoms or side effects that bother you so they can help you manage them.

**Ask your doctor for a survivorship care plan**

Talk with your doctor about developing a survivorship care plan for you. This plan might include:

- A suggested schedule for follow-up exams and tests
- A schedule for other tests you might need in the future, such as early detection (screening) tests for other types of cancer, or tests to look for long-term health effects from your cancer or its treatment
- A list of possible late- or long-term side effects from your treatment, including what to watch for and when you should contact your doctor
- Diet and physical activity suggestions
- Reminders to keep your appointments with your primary care provider (PCP), who will monitor your general health care

**Keeping health insurance and copies of your medical records**

Even after treatment, it’s very important to keep health insurance. Tests and doctor visits cost a lot, and even though no one wants to think about their cancer coming back, this could happen.

At some point after your cancer treatment, you might find yourself seeing a new doctor who doesn’t know about your medical history. It’s important to keep copies of your medical records to give your new doctor the details of your diagnosis and treatment. Learn more in Keeping Copies of Important Medical Records.
Can I lower my risk of Kaposi sarcoma progressing or coming back?

If you have (or have had) Kaposi sarcoma, you probably want to know if there are things you can do that might lower your risk of the cancer growing or coming back, such as exercising, eating a certain type of diet, or taking nutritional supplements. Unfortunately, it’s not yet clear if there are things you can do that will help.

Adopting healthy behaviors such as not smoking, eating well, getting regular physical activity, and staying at a healthy weight might help, but no one knows for sure. However, we do know that these types of changes can have positive effects on your health that can extend beyond your risk of Kaposi sarcoma or other cancers.

It is very important for people who have had Kaposi sarcoma to do what they can to keep their immune systems healthy and to limit their risk of infection. If you are HIV-positive, this means being sure to take your antiviral medicines regularly. Talk with your doctor about getting vaccines and other steps you can take to help prevent infections.

About dietary supplements

So far, no dietary supplements (including vitamins, minerals, and herbal products) have been shown to clearly help lower the risk of cancer progressing or coming back. This doesn’t mean that no supplements will help, but it’s important to know that none have been proven to do so.

Dietary supplements are not regulated like medicines in the United States – they do not have to be proven effective (or even safe) before being sold, although there are limits on what they’re allowed to claim they can do. If you’re thinking about taking any type of nutritional supplement, talk to your health care team. They can help you decide which ones you can use safely while avoiding those that might be harmful.

If the cancer comes back

If the cancer does recur at some point, your treatment options will depend on where the cancer is located, what treatments you’ve had before, and your health.

For more information, see Understanding Recurrence.

Getting emotional support

Some amount of feeling depressed, anxious, or worried is normal when KS is a part of
your life. Some people are affected more than others. But everyone can benefit from help and support from other people, whether friends and family, religious groups, support groups, professional counselors, or others. Learn more in Life After Cancer.13

Hyperlinks


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