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After Myelodysplastic Syndrome Treatment

Get information about how to live well after myelodysplastic syndrome treatment and make decisions about next steps.

Living as a Cancer Survivor

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

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Living as a Myelodysplastic Syndrome Survivor

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Since myelodysplastic syndromes (MDS) are very hard to cure, most people with MDS never actually complete treatment. People may go through a series of treatments with rest in between. Some people might choose to stop active treatment in favor of supportive care. Learning to live with cancer that does not go away can be difficult and

very stressful. See [Managing Cancer as a Chronic Illness](#)¹ for more about this.

Follow-up care

Whether or not you're being actively treated for MDS, your doctors will still want to watch you closely, so it's very important to go to all follow-up appointments.

Exams and tests

During follow-up visits, your doctors will ask about symptoms, examine you, and may order blood tests. They will continue to watch for signs of infection or progression to leukemia, as well as for short-term and long-term side effects of treatment. This is a good time for you to ask your health care team any questions you need answered and to discuss any concerns you might have.

Almost any cancer treatment can have side effects. Some may not last long, but others can be permanent. Don't hesitate to tell your care team about any symptoms or side effects that bother you so they can help you manage them.

Keeping health insurance and copies of your medical records

It's very important to keep [health insurance](#)². With a chronic disease like MDS, your treatment may never really be over. You don't want to have to worry about paying for it. Many people have been bankrupted by medical costs.

At some point after your 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](#)³.

Can I lower my risk of the MDS progressing?

If you have MDS, you probably want to know if there are things you can do to reduce your risk of it progressing, such as exercising, eating a certain type of diet, or taking nutritional supplements. At this time, not enough is known about MDS to say for sure if there are things you can do will help.

Adopting healthy behaviors such as [not smoking](#)⁴, [eating well, getting regular physical activity, and staying at a healthy weight](#)⁵ may help, but no one knows for sure. However, we do know that these types of changes can have many other positive effects on your

health, including helping you feel better.

About dietary supplements

So far, no [dietary supplements](#)⁶ (including vitamins, minerals, and herbal products) have been shown to clearly help lower the risk of MDS progressing. 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 don't 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.

Getting emotional support

Some amount of feeling depressed, anxious, or worried is normal when MDS 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. To learn more about this, see [Coping With Cancer](#)⁷.

Hyperlinks

1. www.cancer.org/cancer/survivorship/long-term-health-concerns/cancer-as-a-chronic-illness.html
2. www.cancer.org/cancer/financial-insurance-matters/understanding-health-insurance.html
3. www.cancer.org/cancer/survivorship/long-term-health-concerns/keeping-copies-of-important-medical-records.html
4. www.cancer.org/cancer/risk-prevention/tobacco.html
5. www.cancer.org/cancer/risk-prevention/diet-physical-activity.html
6. www.cancer.org/cancer/managing-cancer/treatment-types/complementary-and-integrative-medicine/dietary-supplements.html
7. www.cancer.org/cancer/survivorship/coping.html

Last Revised: January 22, 2018

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