After Myelodysplastic Syndrome Treatment

Living as a Cancer Survivor

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

- What Happens After Treatment for a Myelodysplastic Syndrome?
- Lifestyle Changes After Having Myelodysplastic Syndrome
- How Does Having Myelodysplastic Syndrome Affect Your Emotional Health?

Cancer Concerns After Treatment

Treatment may remove or destroy the cancer, but it is very common to have questions about cancer coming back or treatment no longer working.

- If Treatment for a Myelodysplastic Syndrome Stops Working

What Happens After Treatment for a Myelodysplastic Syndrome?

Since myelodysplastic syndromes (MDS) are rarely cured, most patients never actually complete treatment. Patients may go through a series of treatments with rest in between. Some people 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 for more about this.

Follow-up care
Even if you have stopped your treatment for MDS, it is still very important to go to all follow-up appointments. During these visits, your doctors will ask about symptoms, physically examine you, and order blood tests. They will continue to watch for signs of infection and progression to leukemia, as well as for short-term and long-term side effects of treatment. This is the 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 last for a few weeks to several months, 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.

It is also important to keep your health insurance. 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.

**Seeing a new doctor**

At some point after your diagnosis and treatment, you may find yourself in the office of a new doctor who does not know your medical history. It is important that you be able to give your new doctor the details of your diagnosis and treatment. Make sure you have this information handy:

- A copy of your pathology report(s) from any biopsies or surgeries
- If you had surgery, a copy of your operative report(s)
- If you were in the hospital, a copy of the discharge summary that doctor prepare when patients are sent home
- Finally, since some drugs can have long-term side effects, a list of your drugs, drug doses, and when you took them

The doctor may want copies of this information for his records, but always keep copies for yourself.

**References**

[See all references for Myelodysplastic Syndromes](#)

Last Medical Review: February 10, 2014 Last Revised: July 2, 2015

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Lifestyle Changes After Having Myelodysplastic Syndrome

You can’t change the fact that you have had cancer. What you can change is how you live the rest of your life – making choices to help you stay healthy and feel as well as you can. This can be a time to look at your life in new ways. Maybe you are thinking about how to improve your health over the long term. Some people even start during cancer treatment.

Making healthier choices

For many people, a diagnosis of cancer helps them focus on their health in ways they may not have thought much about in the past. Are there things you could do that might make you healthier? Maybe you could try to eat better or get more exercise. Maybe you could cut down on the alcohol, or give up tobacco. Even things like keeping your stress level under control may help. Now is a good time to think about making changes that can have positive effects for the rest of your life. You will feel better and you will also be healthier.

You can start by working on those things that worry you most. Get help with those that are harder for you. For instance, if you are thinking about quitting smoking and need help, call the American Cancer Society at 1-800-227-2345 for information and support. This tobacco cessation and coaching service can help increase your chances of quitting for good.

Eating better

Eating right can be hard for anyone, but it can get even tougher during and after cancer treatment. Treatment may change your sense of taste. Nausea can be a problem. You might not feel like eating and lose weight when you don’t want to. Or you might have gained weight that you can’t seem to lose. All of these things can be very frustrating.

If treatment caused weight changes or eating or taste problems, do the best you can and keep in mind that these problems usually get better over time. You may find it helps to eat small portions every 2 to 3 hours until you feel better. You may also want to ask your cancer team about seeing a dietitian, an expert in nutrition who can give you ideas on how to deal with these treatment side effects.

One of the best things you can do after cancer treatment is put healthy eating habits
into place. You may be surprised at the long-term benefits of some simple changes, like increasing the variety of healthy foods you eat. Getting to and staying at a healthy weight, eating a healthy diet, and limiting your alcohol intake may lower your risk for a number of types of cancer, as well as having many other health benefits.

For more information about nutrition, see Nutrition for the Person With Cancer During Treatment.

**Rest, fatigue, and exercise**

Extreme tiredness, called *fatigue*, is very common in people treated for cancer. This is not a normal tiredness, but a “bone-weary” exhaustion that doesn’t get better with rest. For some people, fatigue lasts a long time after treatment, and can make it hard for them to exercise and do other things they want to do. But exercise can help reduce fatigue. Studies have shown that patients who follow an exercise program tailored to their personal needs feel better physically and emotionally and can cope better, too.

If you were sick and not very active during treatment, it is normal for your fitness, endurance, and muscle strength to decline. Any plan for physical activity should fit your own situation. A person who has never exercised will not be able to take on the same amount of exercise as someone who plays tennis twice a week. If you haven’t exercised in a few years, you will have to start slowly – maybe just by taking short walks.

Talk with your health care team before starting anything. Get their opinion about your exercise plans. Then, try to find an exercise buddy so you're not doing it alone. Having family or friends involved when starting a new exercise program can give you that extra boost of support to keep you going when the push just isn’t there.

If you are very tired, you will need to balance activity with rest. It is OK to rest when you need to. Sometimes it's really hard for people to allow themselves to rest when they are used to working all day or taking care of a household, but this is not the time to push yourself too hard. Listen to your body and rest when you need to. For more information on dealing with fatigue, see [Fatigue in People With Cancer](#) and [Anemia in People With Cancer](#).

Keep in mind exercise can improve your physical and emotional health.

- It improves your cardiovascular (heart and circulation) fitness.
- Along with a good diet, it will help you get to and stay at a healthy weight.
- It makes your muscles stronger.
- It reduces fatigue and helps you have more energy.
• It can help lower anxiety and depression.
• It can make you feel happier.
• It helps you feel better about yourself.

And long term, we know that getting regular physical activity plays a role in helping to lower the risk of some cancers, as well as having other health benefits.

• References
See all references for Myelodysplastic Syndromes

How Does Having Myelodysplastic Syndrome Affect Your Emotional Health?

At some point, you may find yourself overcome with many different emotions. This happens to a lot of people. You may have been going through so much at first that you could only focus on getting through each day. Now it may feel like a lot of other issues are catching up with you.

You may find yourself thinking about death and dying. Or maybe you’re more aware of the effect the cancer has on your family, friends, and career. You may take a new look at your relationship with those around you. Unexpected issues may also cause concern. For instance, if you start feeling better and have fewer doctor visits, you will see your health care team less often and have more time on your hands. These changes can make some people anxious.

Almost everyone who has been through cancer can benefit from getting some type of support. You need people you can turn to for strength and comfort. Support can come in many forms: family, friends, cancer support groups, church or spiritual groups, online support communities, or one-on-one counselors. What’s best for you depends on your situation and personality. Some people feel safe in peer-support groups or education groups. Others would rather talk in an informal setting, such as church. Others may feel
more at ease talking one-on-one with a trusted friend or counselor. Whatever your source of strength or comfort, make sure you have a place to go with your concerns.

The cancer journey can feel very lonely. It is not necessary or good for you to try to deal with everything on your own. And your friends and family may feel shut out if you do not include them. Let them in, and let in anyone else who you feel may help. If you aren’t sure who can help, call your American Cancer Society at 1-800-227-2345 and we can put you in touch with a group or resource that may work for you.

References
See all references for Myelodysplastic Syndromes

If Treatment for a Myelodysplastic Syndrome Stops Working

If your myelodysplastic syndrome (MDS) does not improve with one treatment, it is often possible to try another treatment plan to help you live longer and feel better. But if you have tried many different treatments without improvement, your disease may be resistant to treatment. If this happens, it’s important to weigh the possible limited benefits of a new treatment against the possible downsides. Everyone has their own way of looking at this.

This is likely to be the hardest part of your battle with MDS – when you have been through many medical treatments and nothing’s working anymore. Your doctor may offer you new options, but at some point you may need to consider that treatment is not likely to improve your health or change your outcome or survival.

If you want to continue to get treatment for as long as you can, you need to think about the odds of treatment having any benefit and how this compares to the possible risks and side effects. In some cases, your doctor can estimate how likely it is the MDS will respond to the treatment you are considering. For instance, the doctor may say that chemo might have about a 1% chance of working. Some people are still tempted to try
this. But it is important to think about and understand your reasons for choosing this plan.

No matter what you decide to do, you need to feel as good as you can. Make sure you are asking for and getting treatment for any symptoms you might have, such as nausea or pain. This type of treatment is called **palliative care**.

**Palliative care** helps relieve symptoms, but is not expected to cure the disease. It can be given along with cancer treatment, or can even be cancer treatment. The difference is its purpose - the main purpose of palliative care is to improve the quality of your life, or help you feel as good as you can for as long as you can. Sometimes this means using drugs to help with symptoms like pain or nausea. Sometimes, though, the treatments used to control your symptoms are the same as those used to treat cancer. For instance, radiation might be used to help relieve bone pain caused by cancer that has spread to the bones. Or chemo might be used to help shrink a tumor and keep it from blocking the bowels. But this is not the same as treatment to try to cure the cancer.

At some point, you may benefit from hospice care. This is special care that treats the person rather than the disease; it focuses on quality rather than length of life. Most of the time, it is given at home. Your cancer may be causing problems that need to be managed, and hospice focuses on your comfort. You should know that while getting hospice care often means the end of treatments such as chemo and radiation, it doesn’t mean you can’t have treatment for the problems caused by your cancer or other health conditions. In hospice the focus of your care is on living life as fully as possible and feeling as well as you can at this difficult time. You can learn more about hospice in [Hospice Care](#) and [Nearing the End of Life](#).

Staying hopeful is important, too. Your hope for a cure may not be as bright, but there is still hope for good times with family and friends – times that are filled with happiness and meaning. Pausing at this time in your cancer treatment gives you a chance to refocus on the most important things in your life. Now is the time to do some things you’ve always wanted to do and to stop doing the things you no longer want to do. Though the cancer may be beyond your control, there are still choices you can make.

- [References](#)
- [See all references for Myelodysplastic Syndromes](#)

Last Medical Review: February 10, 2014 Last Revised: July 2, 2015